

Bond University

DOCTORAL THESIS

Biomedical and Clinical Markers, Illness Perceptions, Coping, Benefit Finding, Adjustment, and Treatment Outcomes in Hepatitis C: A Self-Regulatory, Biopsychosocial Model.

Langston, Simon

Award date:
2017

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.



BOND UNIVERSITY

**Biomedical and Clinical Markers, Illness Perceptions, Coping, Benefit
Finding, Adjustment, and Treatment Outcomes in Hepatitis C: A Self-
Regulatory, Biopsychosocial Model**

Simon A. Langston

Submitted in total fulfilment of the requirements of the degree of

Doctor of Philosophy (PhD)

October, 2017

Faculty of Society and Design

Primary Supervisor: Professor Mark S. Edwards

Secondary Supervisor: Dr Mike Lyvers

Index

Acknowledgments	iii
Thesis Summary	iii
Abstract	iv
List of Tables	viii
List of Figures	ix
Publications	x
Table of Contents	xi
List of Appendices	xiv

Acknowledgements

I would like to primarily thank Dr Mark Edwards for his tireless and unwavering support of this project, along with Dr Mike Lyvers and Dr Peta Stapleton for all their valuable contributions over the life of this PhD journey.

Thesis Summary

Hepatitis C virus (HCV) is a potentially chronic illness that has been associated with physical and psychological co-morbidity. An expanded self-regulatory model of illness, which incorporates illness perceptions and coping strategies, and benefit finding, demonstrated utility in predicting physical and psychological adjustment among individuals with HCV. Further, illness perceptions related to treatment control, benefit finding, and depression predicted HCV treatment response after controlling for demographic and biomedical markers.

Simon A. J. Langston (2017).

Abstract

Objectives. Study 1.1 investigated whether illness perceptions, adaptive and maladaptive coping strategies, and benefit finding predicted physical and psychosocial adjustment in individuals diagnosed with hepatitis C virus (HCV) within an expanded self-regulatory model of illness (SRM). Study 1.1 also determined whether coping strategies and benefit finding mediated the relationship between illness perceptions and physical and psychosocial adjustment outcomes. Study 1.2 assessed whether coping strategies independently accounted for variance in adjustment and the role of illness perceptions in predicting adjustment after controlling for coping strategies. Study 2.1 investigated whether illness perceptions and adaptive and maladaptive coping strategies predicted Hepatitis C (HCV) treatment outcomes after controlling for clinical, behavioural and demographic markers relevant to HCV. Study 2.2 assessed whether benefit finding predicted HCV treatment response after controlling for treatment control, substance use and mental health. Study 2.3 investigated whether physical (physical health) and psychosocial adjustment (depression, life satisfaction, and positive affect) predicted HCV treatment response after controlling for substance use and mental health comorbidity.

Method. For Studies 1.1 and 1.2, a total of 126 participants with HCV completed an online questionnaire assessing illness perceptions, coping, benefit finding, and depression, physical functioning, life satisfaction and positive affect as the adjustment outcomes. For Studies 2.1, 2.2 and 2.3, thirty two participants with HCV completed two online questionnaires at Time 1 (pre-HCV treatment) and Time 2 (three months post commencement of HCV treatment). At time 1 clinical,

behavioural and demographic data were collected as were and measures of illness perceptions and coping. At time 2 HCV treatment adherence and HCV treatment response were measured.

Results. In Study 1.1, illness perceptions (personal control, identification with HCV symptoms, perceptions related to illness duration, illness coherence, and emotional responses to HCV) predicted psychosocial and physical adjustment. The combined contribution of adaptive and maladaptive coping strategies also explained significant variance in adjustment. Greater more maladaptive coping strategies predicted poorer physical health, higher depression, greater life satisfaction, and positive affect outcomes, whereas greater engagement with adaptive coping strategies predicted higher positive affect. More benefit finding predicted positive affect, greater life satisfaction, and higher depression. Mediation tests revealed maladaptive coping strategies mediated the relationships between illness identity and depression, and emotional response and depression, and partially mediated the relationship between illness identity and physical health. Benefit finding mediated the relationships between personal control and positive affect, and personal control and life satisfaction. Study 1.2 demonstrated that maladaptive coping strategies independently accounted for variance in depression, physical health, and positive affect adjustment outcomes. Adaptive coping strategies independently predicted more life satisfaction and positive affect. After controlling for coping strategies, personal control accounted for variance in depression, physical health, life satisfaction, and positive affect. Greater identification with HCV illness symptoms predicted greater depression, lower illness identity scores predicted better physical health, shorter perceptions related to illness timeline predicted increased life satisfaction, and greater negative

emotional responses to HCV predicted lower positive affect. In Study 2.1, treatment control was the only predictor of HCV treatment response. A greater belief in the efficacy of HCV treatment protocols predicted treatment response (i.e. blood test results indicating nil detection of HCV). Coping strategies failed to make any significant contributions to the predictive model. The only clinical variables that predicted response outcome were substance use and mental health comorbidity. Recreational drug use and mental health comorbidity predicted HCV treatment response. In Study 2.2, lower benefit finding predicted treatment response. Consistent with results reported in Study 2.1, treatment control continued to predict HCV treatment response. In Study 2.3 lower depression emerged as the sole predictor of HCV treatment response.

Conclusions. The cross-sectional studies reported in the present thesis demonstrate an important role for adaptive and maladaptive coping strategies in the prediction of physical and psychosocial adjustment among individuals with HCV, regardless of their order of entry into SRM predictive models. In the longitudinal studies, the results demonstrate the important role of illness perceptions related to treatment control in predicting HCV treatment response, and provided support for including HCV pre-treatment psychological interventions to address maladaptive illness perceptions for individuals preparing for HCV treatment. Importantly, the results reported in Study 2.3 provided support for the assessment of depression for individuals preparing for HCV treatment.

List of Tables

Table 6.1:	Sample Characteristics	56
Table 6.2	Descriptive Statistics for Predictor and Criterion Variables (N = 126)	62
Table 6.3	Inter-correlations among Study Predictors.	63
Table 6.4	Unstandardised Coefficients, Beta Weights and 95% Confidence Intervals for Hierarchical Regression Analyses for the Prediction of each Outcome Variable by the Predictor Variables (N=126)	67
Table 6.5	Unstandardised Coefficients, Beta Weights and 95% Confidence Intervals for Multiple Regression Analyses for the Prediction of each Outcome Variable by the Coping Strategies and Illness Perception Components (N = 126)	94
Table 7.1	Biomedical, Demographic, behavioural and clinical data (N = 32)	104
Table 7.2	Means and standard deviations for the illness perception variables and coping strategies as a function of treatment response	108
Table 7.3	Results of logistic regression for predicting treatment response in patients with HCV	109
Table 7.4	Means and standard deviations for the illness perception variable and benefit finding as a function of treatment response	116
Table 7.5	Results of logistic regression for predicting treatment response in patients with HCV	117
Table 7.6	Means and standard deviations for the study dependent variables as a function of treatment response	124

Table 7.7	Results of logistic regression for predicting treatment response in patients with HCV	125
-----------	---	-----

List of Figures

Figure 6.1	The direct and mediated pathways between illness identity and depression	70
Figure 6.2	The direct and mediated pathways between emotional response and depression	71
Figure 6.3	The direct and mediated pathways between illness identity and physical health	72
Figure 6.4	The direct and mediated pathways between personal control and life satisfaction	74
Figure 6.5	The direct and mediated pathways between personal control and positive affect	75

Publications

- Langston, S., Edwards, M. S., Lyvers, M., & Stapleton, P. (2016). Illness perceptions and treatment outcomes in Hepatitis C. *New Zealand Journal of Psychology, 45*, 22-28.
- Langston, S., Edwards, M. S., & Lyvers, M. (2016). Illness perceptions, coping, benefit finding, and adjustment in individuals with Hepatitis C. *Australian Psychologist*. doi: 10.1111/ap.12255.
- Langston, S., Edwards, M. S., Lyvers, M., & Stapleton, P. (2017). The self-regulatory model and adjustment outcomes in Hepatitis C. *Professional Psychology: Research and Practice*. doi: 10.1037/pro0000136.

Table of Contents

Chapter 1	1
Thesis Overview	1
Chapter 2	5
An Introduction to Hepatitis C	5
2.1 HCV Overview	5
2.2 Summary	13
Chapter 3	14
Chronic Disease and Physical and Psychosocial Adjustment	14
Chapter 4	20
The SRM	20
4.1 Introduction to the SRM	20
4.2 Illness Perceptions	24
4.3 Coping and the SRM	27
4.4 Benefit Finding and HCV	30
4.5 Summary of Limitations in the Current Literature	34
4.6 Aims of the Present Thesis	36
Chapter 5	41
General Method	41
5.1 Participants	41
5.2 Biomedical, Clinical, Behavioural and Demographic Information	41
5.3 Illness Perceptions	42
5.4 Coping	43

5.5 Benefit Finding	44
5.6 Depression	44
5.7 Life Satisfaction	45
5.8 Positive Affect	46
5.9 Physical Health	46
5.10 Treatment Outcome Assessment (Time 2)	47
5.11 Procedure	48
Chapter 6	49
Study 1.1 - Illness Perceptions, Coping, Benefit Finding, and Adjustment in Hepatitis C	49
6.1 Introduction	49
6.2 Methods	56
<i>6.2.1 Participants</i>	56
<i>6.2.2 Measures</i>	57
<i>6.2.3 Procedure</i>	58
<i>6.2.4 Results</i>	59
6.3 Discussion	75
6.4 General comments	87
Study 1.2 - The Role of Coping in Adjustment Outcomes in Hepatitis C	88
6.5 Introduction	88
6.6 Methods	90
<i>6.6.1 Data Analysis</i>	90
<i>6.6.2 Results</i>	90

6.7 Discussion	95
6.8 General Comments	99
Chapter 7	101
Study 2.1- Illness Perceptions, Coping and Treatment	
Outcomes in Hepatitis C	101
7.1 Introduction	101
7.2 Method	103
7.2.1 <i>Participants</i>	103
7.2.2 <i>Measures</i>	104
7.2.3 <i>Procedure</i>	105
7.2.4 <i>Statistical Analysis</i>	106
7.2.5 <i>Results</i>	106
7.3 Discussion	110
7.4 General Comments	113
Study 2.2 Biomedical Markers, Illness Perceptions, Benefit Finding and Hepatitis	
C Treatment Outcomes	114
7.5 Introduction	114
7.6 Method	115
7.6.1 <i>Results</i>	115
7.7 Discussion	117
7.8 General Comments	119
Study 2.3. Depression, Physical Health, Life Satisfaction, Positive Affect and	
Treatment Response Outcomes in HCV	121
7.9 Introduction	121
7.10 Method	123

7.10.1 Results	123
7.11 Discussion	125
7.12 General Comments	126
Chapter 8	127
General Discussion	127
8.1 Overview	127
8.2 Relations Between Illness Perceptions, Coping, Benefit Finding, and Physical and Psychosocial Adjustment – Review of Cross-Sectional Models	127
8.3 Relations Between Illness Perceptions, Coping, Benefit Finding, and HCV Treatment Response – Review of Longitudinal Models	140
8.4 Review of Supplementary Longitudinal Study	143
8.5 Empirical Limitations	144
8.6 Conclusion and Future Directions	146
References	147
List of Appendices	181
A: Expanded Self-Regulatory Model of Illness	181
B: On-line Survey 1	183
C: On-line Survey 2	207
D: Participant Information Sheet	209
E: Consent Acknowledgement	213
F: The Research Invitation Flyer	214
G: Journal Papers	215

Chapter 1

Thesis Overview

Hepatitis C (HCV) is a high prevalence blood borne disease (approximately 170 million individuals worldwide currently live with the disease), often chronic in nature, that has been associated with a number of physical comorbidities such as cirrhosis of the liver, hepatocellular carcinoma, musculoskeletal pain, cognitive impairment (Bacon, Farahvash, Janney, & Neuschwander, 1994; Barkhuizen et al., 1999; Bayard, Holt, & Boroughs, 2006; Benvegna, Gios, Boccato, & Alberti, 2004; Chapko et al., 2005; Chen & Morgan, 2006; Forton, Taylor-Robinson, & Thomas, 2003; Fried et al., 2002; Friedman, 1999; Glacken, Coates, Kernohan, & Hegarty, 2003; Hauser, Zimmer, Schiedermaier, & Grandt, 2004; Hoofnagle, 1997; Koziel, 2005; Lee & Harrison, 2005; Lehman & Cheung, 2002; Mendez et al., 2001; Ramalho, 2003; Shiffman et al., 2004; Simmonds, 2001), and psychological comorbidities such as depression and anxiety (Chapko et al., 2005; Chen & Morgan, 2006; Fried et al., 2002; Hauser et al., 2004; Lee & Harrison, 2005; Shiffman et al., 2004; Simmonds, 2001). Despite the potential for individuals to clear HCV through anti-viral treatment regimens, there is considerable variance in treatment outcomes (Bianchi et al., 2000; Shiffman et al., 2004), and unlike other types of Hepatitis, such as Hepatitis B (HBV), there is currently no vaccine to protect individuals from contracting it (Choo et al., 1989; Coppola et al., 2004; Shiffman et al., 2004). To date much of the research in HCV has focussed on developing biomedical treatment models (Cheng, Bonis, Lau, Pham, & Wong, 2001; Chen & Morgan, 2006; Lee & Abdo, 2003; Shiffman et al., 2004). There has been a corresponding paucity of research on the role of psychological variables in predicting biomedical HCV treatment outcomes. Similarly, despite the strong

association between chronic HCV and physical and psychological comorbidity (Barkhuizen et al., 1999; Bonkovsky et al., 2007; Chen & Morgan, 2006; Forton et al., 2003; Glacken et al., 2003; Hauser et al., 2004; Law et al., 2001; Lehman & Cheung, 2002; Mendez et al., 2001; Neri, Pulvirenti, & Bertino, 2006; Rothenhausler et al., 2009; Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003), a relatively limited number of published studies had focussed on the role of psychological variables in predicting physical and psychosocial adjustment among individuals living with HCV. In addressing these gaps in HCV research, the primary aims of the present thesis were to test: (1) whether psychological variables could predict biomedical treatment response after controlling for biomedical markers identified in previous HCV research as having important links to treatment outcomes (e.g., Shiffman et al., 2004), and (2) assess how well psychological variables could explain variance in physical and psychosocial adjustment among individuals living with HCV. A supplementary aim of the present thesis was to determine if physical and psychosocial adjustment variables could predict HCV treatment response after controlling for biomedical markers identified in previous research as having links with HCV treatment outcomes (Lee & Abdo, 2003).

In order to achieve the aims of the present thesis, two studies, one cross-sectional and one longitudinal, were conducted that utilised the self-regulatory model of illness (SRM) and benefit finding to assess the effectiveness of psychological variables to predict both treatment response, and physical and psychosocial adjustment within the context of HCV (Helgeson, Reynolds, & Tomich, 2006; Leventhal, Meyer, & Nerenz, 1980). The SRM posits that illness perceptions and coping strategies guide self-management behaviours in response to illness, and are therefore linked to health related outcomes (Hagger & Orbell,

2003; Leventhal et al., 1980; Leventhal, Diefenbach, & Leventhal, 1992). A number of studies have measured the effectiveness of the SRM in predicting biomedical, physical and psychosocial adjustment outcomes across related chronic diseases (Broadbent et al., 2015; Chilcot, Wellsted, & Farrington, 2011; Hagger & Orbell, 2003). Benefit finding has been described as a process where individuals find benefits or meaning in response to adverse life events (e.g., the experience of chronic disease) leading to positive physical and psychosocial outcomes (Fortune, Richards, Griffiths, & Main, 2005; Helgeson et al., 2006; McMillen & Fisher, 1998; Pakenham, 2007; Pakenham, 2011; Rogan, Fortune, & Prentice, 2013; Seligman & Csikszentmihalyi, 2000; Siegal & Scrimshaw, 2000; Stanton, Bower, & Low, 2006; Thompson, 1985). A growing number of studies have shown that benefit finding accounted for variance in biomedical treatment, physical and psychosocial adjustment outcomes across multiple chronic disease conditions (de Ridder, Geenen, Kuijer, & van Middendorp, 2008; Helgeson et al., 2006; Littlewood, Venable, Carey, & Blair, 2008; Luszczynska, Sarkar, & Knoll, 2007; McMillen & Fisher, 1998; Park, Chmielewski, & Blank, 2009; Tennen, Affleck, Urrows, Higgins, & Mendola, 1992).

Chronic disease conditions such as HCV, by their very nature, have the potential to disrupt individuals' lives physically, emotionally, and socially (de Ridder et al., 2008). For example, mood disturbance, decreased physical functioning, and reduced satisfaction with life are commonly reported as comorbid problems across a range of chronic disease conditions (de Ridder et al., 2008; Rutter & Rutter, 2002). No published research to date has specifically investigated the links between depression, physical health as defined by reported physical functioning, role limitations due to health concerns, reported bodily pain, and

general health perceptions, quality of life as measured by reported satisfaction with life, positive affect, and HCV treatment response. Therefore, the final longitudinal study reported here assessed whether physical health and psychosocial adjustment measures, (depression, life satisfaction, and positive affect) predicted HCV treatment response.

The thesis is organised into several sections. The introductory chapters review HCV, chronic disease and adjustment, the SRM, illness perceptions and coping, and an overview of the benefit finding model. In Chapters 6 and 7 the two empirical studies and their sub-components are reported. Chapter 8 reconciles the data with respect to the existing empirical literature and suggestions for future research are offered.

Chapter 2

An Introduction to Hepatitis C

2.1 HCV Overview

HCV is a potentially chronic viral illness caused by contact with infected blood and is the leading cause of liver related morbidity and mortality in the world (Chapko et al., 2005; Chen & Morgan, 2006; Fried et al., 2002; Golden, Conroy, O'Dwyer, Golden, & Hardouin, 2006; Hauser et al., 2004; Lee & Abdo, 2003; Lee & Harrison, 2005; Rothenhausler et al., 2009; Shiffman et al., 2004; Simmonds, 2001). HCV treatment costs have a significant impact on the national economy, and it is not uncommon for individuals with HCV to experience illness related stigmatisation, mental health problems, and discrimination across a range of social, healthcare and employment areas given its strong public association with intravenous (IV) drug use (Butt, 2008; Brener, Von Hippel & Kippax, 2007; Department of Health and Ageing, 2005; Golden et al., 2006; Paterson, Backmund, Hirsch, & Yim, 2007; Sacks et al., 2004; Zacks et al., 2006; Zickmund et al., 2003). Unlike other types of Hepatitis, such as Hepatitis B, no vaccine currently exists to protect individuals from contracting HCV (Coppola et al., 2004).

Approximately 170 million people worldwide, or around 2% of the world's population, are chronically infected by HCV (Chen & Morgan, 2006; Hanafiah, Groeger, Flaxman, & Wiersma, 2013; Rothenhausler et al., 2009). Each year in Australia approximately 264,000 people are exposed to HCV, and of these, approximately 9,700 become infected (Australian National Council on AIDS, Hepatitis C and Related Diseases, Hepatitis C Sub-Committee, 2002; Batey, 2002; Butler & Quinn, 2003; Crofts, Aitken, & Kaldor, 1999; Department of Health and Ageing, 2005; Hepatitis C Virus Projections Working Group, 2002; Law et al.,

2001; Levy, Baum, & Thomas, 2002; National Centre in HIV Epidemiology and Clinical Research, 2004). Recent data suggest that in Australia, approximately 270,000 individuals live with chronic HCV infection (Gane et al., 2014).

An estimated 90% of individuals who have been chronically infected with HCV never receive treatment (Department of Health and Ageing, 2005; Economic Evaluation of Hepatitis C in Australia, 2005; National Centre in HIV Epidemiology and Clinical Research, 2010). For the purposes of the present thesis, a chronic disease is defined as a health condition that generally exists for periods of time greater than three months (Hagger & Orbell, 2003; Vaughan, Morrison, & Miller, 2003). When left untreated HCV can lead to a number of medical complications such as liver failure, liver cancer and death (Economic Evaluation of Hepatitis C in Australia, 2005). In the 2004 – 2005 financial year, approximately 1,500 deaths in Australia were attributed to the effects of chronic HCV (Department of Health and Ageing, 2005; Economic Evaluation of Hepatitis C in Australia, 2005).

Australian data suggest that approximately 7% of new HCV cases result from exposure unrelated to IV drug use (Department of Health and Ageing, 2005). Examples of this type of transmission can include exposure to contaminated blood products, receiving tattoos, and in rare cases through mother to infant contact (Department of Health and Ageing, 2005; Heintges, & Wands, 1997; Newell & Pembrey, 2002). The remaining 93% of new HCV infections each year in Australia are directly attributed to IV drug use (Australian National Council on AIDS, Hepatitis C and Related Diseases, Hepatitis C Sub-Committee, 2002; Crofts et al., 1999; Crofts, 2001; Law & Batey, 2003; National Centre in HIV Epidemiology and Clinical Research, 2007).

Despite many cases presenting as relatively asymptomatic during the initial acute phase of infection, in over 80% of cases, HCV develops into a persistent chronic illness and can be the cause of a myriad of serious health conditions including liver failure (often requiring a liver transplant), cirrhosis of the liver, hepatocellular carcinoma, hepatic steatosis, cellular immune dysfunction, musculoskeletal pain, chronic fatigue, cognitive impairment, abdominal pain, nausea, decreased appetite, in rare cases vasculitis and peripheral neuropathy, and mental health conditions, such as depression, anxiety and mood swings (Barkhuizen et al., 1999; Chen & Morgan, 2006; Dusheiko, 1996; Forton et al., 2003; Fried et al., 2002; Glacken et al., 2003; Hoofnagle, 1997; Iosue, 2002; Koziel, 2005; Lee & Abdo, 2003; Lee & Harrison, 2005; Lehman & Cheung, 2002; Lieber, 2001; Mendez et al., 2001; Ramalho, 2003).

Since the identification of HCV in 1989 (previously known as either non-A or non-B hepatitis), antiviral therapies have been developed and administered, which seek to clear the virus or achieve a sustained virological response (Alter, 1997; Fried et al., 2002; Greenberger, 1998; Iosue, 2002; Koff, 2000; Lee & Abdo, 2003; Lee & Harrison, 2005; Lin & Keefe, 2001; Moussalli, Opolon, & Poynard, 2002; Pawlotsky, 2003; Shiffman et al., 2004; Schaefer et al., 2007; Schaefer & Mauss, 2008; Schreiber, Busch, Kleinman, & Korelitz, 1996; Soffredini et al., 2004). A sustained virological response is defined by HCV being undetectable in the individual's blood six months after completing treatment (Fried et al., 2002; Koff, 2000; Lee & Abdo, 2003; Pawlotsky, 2003; Soffredini et al., 2004). Research has shown that over 95% of patients who achieve a sustained virological response remain free of the virus permanently (Lee & Abdo, 2003).

A wealth of research has focussed on determining important demographic and biomedical markers in predicting HCV treatment outcomes (Lee & Abdo, 2003; Lee & Harrison, 2005; Martinot-Peignoux et al., 1998; Shiffman et al., 2004; Shiratori & Omata, 2000; Vik et al., 2005). For example, Shiffman et al. (2004) conducted research to determine which individual demographic and biomedical factors predicted treatment outcomes among a group of previous treatment non-responders. Results showed that the following factors were associated with an increased probability of the individual achieving a sustained viral response: (1) previous treatment with interferon monotherapy, (2) HCV genotypes 2 or 3, (3) lower HCV serum levels, (4) achievement of a 12 week early viral response, (5) an aspartate transaminase (AST): alanine transaminase (ALT) ratio less than 1.0, and (6) the absence of cirrhosis of the liver, along with the following behavioural predictors: (1) medication adherence, and (2) dosage compliance. By definition, an individual attained a sustained viral response if they achieved 'nil HCV detected' in two sequential blood tests taken at end of treatment and then at six months post end of treatment (Lee & Abdo, 2003; Shiffman et al., 2004). Similarly, Lee and Abdo (2003) identified the individual demographic and biomedical factors that are important in predicting HCV treatment response. Their review of the literature revealed that: (1) HCV genotypes 2 or 3, (2) lower HCV serum levels, (3) combined interferon and ribavirin therapy, (4) shorter duration of HCV infection, (5) younger age (<40 years), (6) body weight (BMI within normal range), (7) the absence of illicit drug use, (8) the absence of cirrhosis or fibrosis of the liver, (9) lower hepatic iron levels, (10) low HCV heterogeneity, (11) female gender, (12) a low AST:ALT ratio, (13) the absence of both medical and mental health comorbidity, and (14) a 4 week rapid viral response or a 12 week early viral

response, were all associated with an increased probability of the patient achieving a sustained viral response (Lee & Abdo, 2003). The present thesis explored whether illness perceptions and coping (features of the SRM), benefit finding, and physical and psychosocial variables predicted HCV treatment response (nil HCV detected in any of the 3, 6, and 12 week milestone blood tests taken during treatment) after controlling for the following demographic, clinical and behavioural markers: (1) age, (2) body weight, (3) HCV genotype, (4) gender, (5) likely route of infection, (6) presence of cirrhosis of the liver, (7) other medical condition/s, (8) recreational drug use, (9) alcohol consumption, (10) smoking cigarettes, (11) comorbid mental health condition/s, (12) previous HCV treatment, and (13) HCV treatment adherence.

At the time the data were collected for the present study, the standard treatment protocol for HCV included interferon (once weekly self-administered intramuscular injection), ribavirin (daily oral self-administered medication), and depending on pre-treatment medical assessment results, an additional protease inhibitor drug (either boceprevir or telaprevir) (Gross et al., 2003; Hallinan, Byrne, Kingsley, & Dore, 2007; Hepatitis C in Australia, 2007; Jacobson et al., 2012; Kaiser, Hass, & Gregor, 2004; Shiffman et al., 2004; Thompson, 2016; Wackernah, Lou, & Park, 2011). Similar to ribavirin, boceprevir and telaprevir require the individual to take an oral tablet on a daily basis for the specified treatment period (Jacobson et al., 2012). Treatment periods for individuals undergoing interferon, ribavirin and protease inhibitor HCV treatment can be between 12 to 48 weeks depending on pre-treatment medical assessment results (e.g., cirrhosis of the liver typically requires longer treatment) (Jacobson et al., 2012; Wackernah et al., 2011).

For individuals preparing for interferon based HCV treatment, a comprehensive psychosocial assessment is often required, in addition to other pre-treatment biomedical assessments, to determine the individual's psychological preparedness for treatment (Thompson, 2016). The rationale for the inclusion of pre-treatment psychosocial assessments is primarily due to the high number of potential side effects that can be experienced by individuals undergoing HCV treatment. Examples of treatment side effects can include nausea, fatigue, joint and muscle pain, chills, fever, anemia, skin conditions, memory loss, apathy, neutropenia, psychosis and depression (Foster, 2010; Fried et al., 2002; Hassanein et al., 2004; Ho et al., 2001; Lee & Harrison, 2005; Moussalli et al., 2002). Further, interferon has been identified as having the potential to exacerbate existing mental health conditions, and may cause endogenous depression or in rare cases, psychosis (Holmes, Thompson, & Bell, 2013; Sarkar, Sarkar, Berg, & Schaefer, 2015; Wackernah et al., 2011).

More recently, a new interferon-free generation of direct-acting anti-viral medications (eg., sofosbuvir, ledipasvir, and daclatasvir), with fewer reported side effect profiles and higher HCV clearance rates in comparison to interferon based treatment protocols, has become available in Australia (Thompson, 2016). However, interferon based HCV treatment protocols remain the standard treatment in many countries across the world (Gane et al., 2014; Wackernah et al., 2011). In Australia, the newer generation direct-acting anti-viral medications are currently funded under the national pharmaceutical benefits scheme (PBS) to treat individuals with HCV genotypes 1, 2 or 3 (Thompson, 2016). Individuals with HCV genotypes 4, 5, or 6 currently remain ineligible to receive subsidised treatment under the PBS for the newer direct-acting anti-viral medications and will

need to continue to receive interferon based HCV treatments for the foreseeable future (Thompson, 2016). Similar inequities exist related to access to newer generation direct-acting anti-viral medications in other parts of the world largely based on treatment cost issues (Gane et al., 2014). For example, in the United States of America, access to the newer generation of direct-acting HCV anti-viral medications is in most cases dependent on the individual's ability to maintain relevant private health insurance cover (Canary, Klevens, & Holmberg, 2015). Further, in many developing countries interferon based HCV protocols continue to remain the standard treatment, largely due to the cost-prohibitive nature of the newer direct-acting anti-viral drugs (Luhmann et al., 2015).

The quality of life costs associated with HCV are potentially both significant and complex (Golden et al., 2006; Iosue, 2002; Lee & Abdo, 2003). For example, common symptoms of HCV can range from mild, and in some cases asymptomatic, to severe and disabling (Barkhuizen et al., 1999; Forton et al., 2003; Glacken et al., 2003; Hassanein et al., 2004; Iosue, 2002; Lee & Harrison, 2005; McHutchison et al., 2001). Further, HCV can have far reaching negative effects on an individual's financial and employment potential, along with, in many cases, reducing their ability to engage in satisfying relationships (Bonkovsky et al., 2007; Golden et al., 2006; Hassanein et al., 2004; McHutchison et al., 2001; Perrillo et al., 2004). For example, Mathew, Peiffer, Rhoades, and McGarrity (2006) examined health related quality of life among a group of individuals with refractory HCV prior to, during, and after undergoing re-treatment with pegylated interferon alpha-2b and ribavirin. Results showed lower health related quality of life at baseline, across a range of indicators including social, emotional and physical functioning, and poorer mental and general health in comparison to

national normative data (Mathew et al., 2006). Similarly, Hollander, Foster and Weiland (2006) conducted a study among a Swedish cohort examining health related quality of life indicators before, during and after combination therapy with interferon and ribavirin in patients with chronic HCV. Results indicated significantly lower quality of life, particularly among previous IV drug users, at baseline when compared to Swedish health related quality of life data (Hollander et al. 2006). Further, Forton et al. (2003) conducted a review analysing the association between chronic HCV and health related quality of life. The findings supported related research that implicated the relationships of fatigue and depression to lower perceived health related quality of life among individuals chronically infected with HCV. The research also identified the possible biological effect that chronic HCV infection can have in contributing directly to neurocognitive impairment independent of substance abuse, depression or hepatic encephalopathy (Forton et al., 2003).

Individuals with HCV commonly experience illness related stigmatisation and discrimination across social, healthcare and employment related areas due to the condition's strong public association with IV drug use (Butt, 2008; Brener et al., 2007; Paterson et al., 2007; Zacks et al., 2006). For example, Zickmund et al. (2003) conducted a cross sectional study measuring perceived illness related stigma among a group of outpatients receiving treatment for HCV. Results demonstrated that a significant proportion of this cohort were experiencing HCV illness related stigma regardless of the route of transmission, along with high levels of depression and anxiety, lower quality of life and perceived ability to cope, and high levels of discrimination across various work, healthcare and personal relationship related domains. Further, stigma were higher among female

participants, but were not influenced by other demographic variables such as level of education, age or occupation (Zickmund et al., 2003). Finally, Golden et al. (2006) conducted a cross sectional study to assess stigma and associated levels of mood disturbance and illness related adjustment among a group of individuals awaiting treatment for HCV. Results revealed high levels of illness related stigma and associated anxiety, depression and low levels of illness related adjustment and overall quality of life among this participant cohort.

2.2 Summary

The present chapter reviewed the physical, social, and economic costs and consequences of living with HCV (Chen & Morgan, 2006; Golden et al., 2006). Further, there are high annual health related costs associated with the treatment of HCV that have a significant impact on government health budgets here in Australia and overseas (Department of Health and Ageing, 2005).

A primary goal of the present thesis was to utilise the SRM, which has demonstrated efficacy in predicting health related outcomes across a range of chronic health conditions within the context of HCV (e.g., Hagger & Orbell, 2003). Before describing in greater detail the features of an expanded SRM, the following chapter: (1) explored some of the key theoretical concepts associated with chronic disease and health related outcomes, (2) reviewed models related to the SRM, and (3) provided a rationale for the use of an expanded SRM in the present thesis.

Chapter 3

Chronic disease and Physical and Psychosocial Adjustment

The present chapter provides a summary of the key theoretical concepts associated with chronic disease and adjustment, and presents a rationale for utilising an expanded SRM, including illness perceptions, coping strategies and benefit finding, as a framework to predict treatment response and physical and psychosocial adjustment among individuals with HCV. Chronic diseases such as HCV can have potentially significant negative impacts on an individual's life (de Ridder et al., 2008; Sprangers et al., 2000). Both acute and chronic illness can reduce overall quality of life in individuals impacted by various medical conditions. Chronic disease can be differentiated from acute illness in terms of duration, the former generally persisting for extended periods of time (de Ridder et al., 2008; Sprangers et al., 2000). The medical impact on an individual living with chronic HCV can range on a continuum from relatively asymptomatic through to significant physical and psychosocial consequences (Barkhuizen et al., 1999; Chen & Morgan, 2006; Forton et al., 2003; Glacken et al., 2003; Hauser et al., 2004; Hoofnagle, 1997; Mendez et al., 2001; Rothenhausler et al., 2009). Prior to the experience of chronic disease, individuals tend to have a habitual set of coping strategies to help them deal with routine and predictable life events. Chronic disease onset however has the potential to force an adjustment of their coping strategies in order to deal with their respective health threat (de Ridder et al., 2008; Taylor & Aspinwall, 1996). Physical and psychosocial adjustments are the end product of the various ways individuals appraise and cope with their chronic disease (de Ridder et al., 2008; Taylor & Aspinwall, 1996). Research has shown that the majority of individuals living with chronic diseases eventually achieve a

positive state of physical and psychosocial adjustment (de Ridder et al., 2008; Taylor & Aspinwall, 1996). However, for around 30% of individuals, positive physical and psychosocial adjustment outcomes remain elusive or unattainable (de Ridder et al., 2008; Taylor & Aspinwall, 1996).

A number of theoretical models have been reported in the literature that investigate links between health related behaviours, the experience of chronic disease and adjustment (Caltabiano & Ricciardelli, 2013; Lazarus & Folkman, 1987). For example, the health belief model (Rosenstock, 1974) investigates the likelihood that individuals will engage in health related behaviours following assessment of perceived seriousness and susceptibility regarding the illness threat, mediated by a cost benefit analysis related to potential success of engaging in health related behaviours, and perceptions related to illness threat and perceived self-efficacy to deal with the health problem (Rosenstock, 1974). Similarly, the theory of planned behaviour investigate links between the assessment of individuals beliefs around behaviour, norms and perceived control and the engagement behaviours, including health related behaviours (Ajzen, 1991). Further, the transactional model of stress and coping outlines a self-regulatory process where by individuals firstly engage in a process of cognitively appraising stressful events in their lives (assessment of perceived levels of risk or harm), including health events, engage in coping behaviours based on their perceived coping resources, and then evaluate the success of their coping behaviours on dealing with these adverse events (Carver, Scheier, & Weintraub, 1989; Lazarus & Folkman, 1987). Within this model a continuous dynamic loop exists between appraisal and re-appraisal of cognitive and coping strategies based on perceived success in dealing with the stressful event identified by the individual (Carver et

al., 1989; Lazarus & Folkman, 1987). Although examples of related health related models described here (Ajzen, 1991; Lazarus & Folkman, 1987; Rosenstock, 1974) reference links between individuals perceptions or attitudes, perceived coping and engagement in health related behaviours, unlike these other models, the SRM includes these perceptions regarding illness related threats into specific illness perception and coping categories or components that can specifically measure links between cognitive and emotional representations of illness, coping strategies and health related outcomes (Leventhal et al., 1992). Further the SRM has been included extensively in research that has investigated links between illness perceptions, coping and health related outcomes (Hagger & Orbell, 2003).

In a review of the literature on adjustment to chronic disease, de Ridder et al. (2008) identified the following key elements that were associated with successful adjustment to chronic disease: (1) the absence of psychological disorders, including depression, (2) positive affect, greater life satisfaction and general quality of life, and (3) adequate physical functioning, including the ability to attend to daily tasks such as work activities. Several models have been proposed that relate to how individuals can achieve better physical and psychosocial adjustment in response to chronic disease (de Ridder et al., 2008). These models have included cognitive adaptation which emphasises illness acceptance and perceived illness related personal control (de Ridder et al., 2008; Taylor, 1983). Other models have focussed on links between various personality factors such as optimism and neuroticism and adjustment (Adler & Matthews, 1994; de Ridder et al., 2008; Taylor, 1983), whereas others have emphasised the role of stress and coping strategies, and the concept of self-regulation in accounting for physical and

psychosocial adjustment (Adler & Matthews, 1994; Cameron & Leventhal, 2003; de Ridder et al., 2008).

Within the context of chronic disease, self-regulation emphasises links between cognitive appraisal of perceived health threats, the adoption of coping strategies and biomedical outcomes, and physical and psychosocial adjustment (Cameron & Leventhal, 2003; de Ridder et al., 2008). Self-regulation related to physical illness refers to the individual actively engaging in cognitive and coping strategies to better manage their health conditions, and has been used to predict physical and psychosocial adjustment, and biomedical treatment outcomes across numerous chronic disease conditions (Cameron & Leventhal, 2003; de Ridder et al., 2008; Sharpe & Curran, 2006; Walker, Jackson, & Littlejohn, 2004). The SRM (Leventhal et al., 1992) shares a number of key features included in related self-regulation based models (Cameron & Leventhal, 2003), i.e., active cognitive appraisal of health related threats included in self-regulation based models, is similar to the formation of cognitive and emotional representations of illness or illness perceptions, and coping behaviours that are activated in response to awareness of an illness threat (Leventhal et al., 1992). Illness perceptions and coping strategies, key features of the SRM, have predicted physical and psychosocial adjustment and biomedical treatment outcomes across a range of chronic disease conditions (Broadbent et al., 2015; Chilcot et al., 2011; Hagger & Orbell, 2003). Therefore, for the present thesis, the SRM provided a strong foundation to test whether illness perceptions and coping strategies could predict physical and psychosocial adjustment, and treatment response, among individuals diagnosed with chronic HCV.

In line with a review conducted by de Ridder et al. (2008), the present thesis utilised measures of depression, quality of life (including positive affect and life satisfaction), and physical health as criterion measures of physical and psychosocial adjustment. Importantly, the SRM has predicted physical and psychosocial adjustment outcomes in other chronic disease conditions, specifically in relation to depression (Fortune, Richards, Griffiths, & Main, 2002; Vaughan, Morrison, & Miller, 2003), quality of life, including life satisfaction and positive affect (De Gucht, 2015; Rutter & Rutter, 2002; Steed et al., 1999), and physical health (Heijmans, 1999; Helder et al., 2002; Scharloo et al., 2000; Steed et al., 1999). Further, similar to related chronic disease research (Chilcot et al., 2011), the present thesis utilised HCV treatment response (nil HCV detected in the bloodstream) as the criterion variable to assess whether the SRM could predict treatment response.

Complementing the cognitive strategies associated with the SRM (e.g., whether beliefs and subsequent coping behaviours predicted adjustment outcomes in chronic disease), research has also focussed on alternative cognitive strategies that enhance positive physical and psychosocial adjustment and improved biomedical treatment outcomes (de Ridder et al., 2008). For example, arising out of positive psychology theory (Seligman & Csikszentmihalyi, 2000), the benefit finding model has been utilised to investigate links between the discovery of benefits or positive meaning following adverse life experiences (including chronic illness) and physical and psychosocial adjustment, and biomedical treatment outcomes (de Ridder et al., 2008; Helgeson et al., 2006; McMillen & Fisher, 1998). In a number of studies, benefit finding accounted for significant variance in physical and psychosocial adjustment, and in a limited number of cases it predicted

biomedical treatment outcomes, across multiple chronic health conditions (Affleck, Tennen, Croog, & Levine, 1987; Bower, Kemeny, Taylor, & Fahey, 1998; Bower et al., 2005; Carver & Antoni, 2004; Danoff-Burg & Revenson, 2005; de Ridder et al., 2008; Sears, Stanton, & Danoff-Burg, 2003; Littlewood et al., 2008; Luszczynska et al., 2007; Park et al., 2009; Tennen et al., 1992). Specific to the present thesis, in studies conducted across chronic disease conditions benefit finding accounted for variance in depression (Carver & Antoni, 2004), quality of life, including life satisfaction and positive affect (Bower et al., 2005), and physical health (Danoff-Burg & Revenson, 2005) adjustment. Similarly, benefit finding predicted biomedical treatment outcomes in a number of chronic disease studies (Affleck et al., 1987; Bower et al., 1998).

In summary, a number of studies have confirmed that illness perceptions and coping strategies (i.e., features of the SRM), and benefit finding have accounted for variance in physical and psychosocial adjustment and predicted biomedical treatment outcomes in chronic disease (Affleck et al., 1987; Bower et al., 1998; Broadbent et al., 2015; Chilcot et al., 2011; Bower et al., 2005; Carver & Antoni, 2004; Danoff-Burg & Revenson, 2005; de Ridder et al., 2008; Hagger & Orbell, 2003; Littlewood et al., 2008; Luszczynska et al., 2007; Park et al., 2009; Tennen et al., 1992). These data provided the rationale to assess whether illness perceptions, coping and benefit finding predicted HCV physical and psychosocial adjustment and treatment response within an expanded SRM. The following chapter reviewed features of the SRM, and evaluated its ability to predict biomedical treatment and physical and psychosocial adjustment outcomes across the spectrum of chronic disease.

Chapter 4

The SRM

4.1 Introduction to the SRM

The SRM is a multidimensional theoretical framework that has been utilised to examine the relationships of illness perceptions and coping strategies to biomedical treatment outcomes and physical and psychosocial adjustment across a range of related chronic disease conditions including irritable bowel syndrome (Boddington, Myers, & Newman, 2002), diabetes (Cartwright & Lamb, 1999), chronic fatigue syndrome (Heijmans, 1998), Addison's disease (Heijmans, 1999), human immuno-deficiency virus (Horne, Cooper, Fisher, Buick, & Weinman, 2001), epilepsy (Kemp, Morley, & Anderson, 1999), Asthma (Horne & Weinman, 2002), rheumatoid arthritis (Moss-Morris et al., 2002), cancer (Rees, Fry, & Cull, 2001), chronic obstructive lung disease (Scharloo et al., 1998), multiple sclerosis (Schiaffino & Cea, 1995), atrial fibrillation (Steed et al., 1999), systematic lupus erythematosus (Daleboudt, Broadbent, McQueen, & Kaptein, 2013), cardiovascular disease (Greco et al., 2014), and hypertension (Theunissen & de Ridder, 2001). The SRM has been the focus of substantial empirical enquiry within the area of cognitive and emotional responses to illness threats (Hagger & Orbell, 2003). Important to the present thesis, no published research has assessed whether the SRM could predict treatment response and physical and psychosocial adjustment among individuals with HCV.

The SRM provides an explanatory framework for understanding how individuals respond to perceived health threats (Broadbent et al., 2006; Broadbent, Kydd, Sanders, & Vanderpyl, 2008; Diefenbach & Leventhal, 1996; Lau & Hartman, 1983; Leventhal et al., 1980; Radat et al., 2009). Within this model,

Leventhal et al. (1980) originally described five cognitive components related to illness perceptions: (a) illness identity (the name or label the individual gives to their illness and the symptoms attributed to the disease), (b) cause (individual beliefs regarding the cause of the health condition), (c) timeline (personal beliefs around how long the condition will last), (d) consequences (perceived impact of the illness on the individual's life), and (e) curability or control (beliefs around illness recovery and degree of personal control over health related outcomes). An additional emotional representation covering negative reactions such as anger, fear and distress was also included in earlier research (Leventhal et al., 1980). Although initial research using the SRM often used open ended interviews to measure these cognitive and emotional representations of illness or illness perceptions (Leventhal et al., 1980), more recent SRM research has employed structured questionnaires such as the Brief Illness Perception Questionnaire (BIPQ: Broadbent et al., 2006). The BIPQ measures eight cognitive and emotional representations or illness perceptions as follows: (a) illness consequence, (b) timeline, (c) personal control, (d) treatment control, (e) illness identity, (f) illness concern, (g) illness coherence or understanding, and (h) emotional response. An additional item measures individual's beliefs around illness causality (Broadbent et al., 2006).

The SRM describes a three stage process following the initial awareness of a health risk (Broadbent et al., 2006; Hagger & Orbell, 2005; Horne & Weinman, 2002; Leventhal et al., 1992). Firstly, in order to reduce the potentially negative effects associated with perceived health risks such as HCV, an individual forms cognitive and emotional representations, or illness perceptions of their health threat (Broadbent et al., 2006). The formation of these representations is influenced by various social, cultural and psychological factors. Examples include previous

illness experiences, and personality and cultural factors related to illness response (Horne & Weinman, 2002; Leventhal et al., 1992). Secondly, these illness perceptions activate coping behaviours in response to the illness threat. Thirdly, the individual then appraises the efficacy of both their perceptions around their illness and coping behaviours in relation to health related outcomes (Broadbent et al., 2006; Leventhal et al., 1992). The SRM incorporates a model based on a *continuous feed-back loop* where the results of the on-going appraisal process are continually fed-back into the first two stages of the process (Broadbent et al., 2006; Hagger & Orbell, 2005; Leventhal et al., 1992). Within this feedback system, both illness representations and coping behaviours are adjusted depending on the perceived success or failure of these illness threat responses or coping behaviours on health related outcomes (Broadbent et al., 2006; Diefenbach & Leventhal, 1996; Hagger & Orbell, 2005; Horne & Weinman, 2002; Leventhal et al., 1992). Therefore, the SRM suggests that illness perceptions and coping behaviours directly account for variance in health related outcomes (Broadbent et al., 2006).

The SRM suggests that following illness awareness, an individual forms perceptions related to their illness. Illness perceptions then trigger coping behaviours, which in turn account for variance in health related outcomes. Therefore, Leventhal et al. (1980) proposed that coping has a potential mediating role between illness perceptions and health related outcomes. According to Baron and Kenny (1986) for mediation to occur as predicted within the SRM, a number of conditions must be met. Firstly, illness perception components must predict health related outcomes. Secondly, illness perceptions must significantly predict coping as the mediating variable. Thirdly, coping must predict the dependent variable, health related outcomes, after controlling for illness perception items.

Finally, the illness perception coefficient value must decrease after including coping into the modelling (Baron & Kenny, 1986).

A number of studies have investigated whether coping strategies mediate the relationship between illness perceptions and health related outcomes in chronic disease (Hagger & Orbell, 2003; Hampson, Glasgow, & Toobert, 1990; Heijmans, 1998; Kemp et al., 1999; Rutter & Rutter, 2002; Scharloo et al., 1998). Relatively few studies have found support for coping to mediate the relationship between illness perceptions and health related outcomes (Hagger & Orbell, 2003; Heijmans, 1998; Kemp et al., 1999; Scharloo et al., 1998). For example, Heijmans (1998) utilised the SRM to investigate whether illness perceptions and coping strategies predicted physical and psychosocial adjustment outcomes among individuals with chronic fatigue syndrome, and whether coping strategies mediated the relationship between illness perceptions and adjustment outcomes. Results confirmed that although illness perceptions alone predicted physical and psychosocial adjustment outcomes, coping strategies did not mediate this relationship (Heijmans, 1998). In comparison, Rutter and Rutter (2002) investigated the role of illness perceptions and coping in predicting health related outcomes among a cohort of irritable bowel syndrome sufferers, and to assess the potential mediating role of coping within this predictive framework. They identified coping as a mediator of the relationship in some, but not all, of the predictive models. For example, in investigating whether illness perception components and coping strategies to account for variance in quality of life outcomes, results identified the use of acceptance as a coping strategy, to mediate the relationship of illness consequences to quality of life outcomes (Rutter & Rutter, 2002). The present thesis provided an opportunity to additionally assess whether coping strategies mediated the relationship between

illness perceptions and physical and psychosocial adjustment outcomes within the context of HCV.

In summary, some tests of the SRM have tended to support the hypothesised relations among its components, though not consistently (Broadbent, 2010; Broadbent et al., 2006; Callegari, Michelini, Sguazzin, Catona, & Klersy, 2005; Dubernard, Rouzier, David-Montefiore, Bazot, & Darai, 2008; Fusar-Poli et al., 2008; Lau & Hartman, 1983; Meyer et al., 1985; Petrie, Weinman, Sharpe, & Buckley, 1996; Petrie, Cameron, Ellis, Buick, & Weinman, 2002; Petrie, Jago, & Devcich, 2007; Pimm & Weinman, 1998; Rothenhausler et al., 2009; Rutter & Rutter, 2002; Steed et al., 1999). To date, the majority of research on the SRM has focussed on related chronic health conditions other than HCV. The present thesis addressed this gap in the literature by investigating whether benefit finding predicted treatment response and physical and psychosocial adjustment among a cohort of individuals preparing for and undertaking HCV treatment, and whether coping strategies mediate these relationships. The following sections describe features of the SRM, illness perceptions and coping, including an evaluation of each of these features to account for variance in biomedical treatment and physical and psychosocial adjustment outcomes across chronic disease conditions.

4.2 Illness Perceptions

The SRM has been used to investigate the illness perceptions of individuals across a range of chronic physical illnesses such as end-stage renal disease, human immuno-deficiency virus, diabetes, heart disease, tuberculosis, and multiple sclerosis (Broadbent et al., 2015; Chilcot et al., 2011; Hagger & Orbell, 2003; Mohammed, Nagla, Morten, Asma, & Arja, 2015; Vaughan et al., 2003). For example, Vaughan et al. (2003) reported that illness perceptions included a strong

illness identity, serious illness consequences, limited illness control, and a more chronic illness timeline in individuals with multiple sclerosis. Additionally, illness perceptions were also linked with weak beliefs associated with a treatment cure, which is consistent with the medical understanding and nature of multiple sclerosis. Previous research has also identified important inter-relationships between each of the illness perception components within the SRM (Buick, 1998; Hagger & Orbell, 2003; Heijmans, 1998; Vaughan et al., 2003). For example, Vaughan et al. (2003) reported that illness identity, chronic timeline, and low personal control were related to greater illness concern. These results highlight and support the need to understand and assess illness perceptions as a group of cognitions, as it appears that once individuals become aware of a medical condition they utilise a number of illness perception components in an effort to make sense of what is happening (Hagger & Orbell, 2003; Vaughan et al., 2003).

The majority of early research exploring the SRM focused on confirming the relationships between illness perceptions, health related behaviours, and coping (Hagger & Orbell, 2003; Hampson et al., 1990). Results from these earlier studies revealed links between illness perceptions and various health related behaviours and coping strategies such as adherence to medication, medical assistance seeking behaviours, and motivation to engage in self-management related activities (Hagger & Orbell, 2003, Hampson et al., 1990; Vaughan et al., 2003). More recent research has begun to explore the relationship between illness perceptions and biomedical treatment outcomes as well as physical and psychosocial adjustment (Broadbent et al., 2015; De Gucht, 2015; Chilcot et al., 2011; Greco et al., 2014; Heijmans, 1998, 1999; Helder et al., 2002; Lee, Chaboyer, & Wallis, 2008; Moss-Morris, Petrie, & Weinman, 1996; Scharloo et al., 1998; Vaughan et al., 2003). A

number of these studies have confirmed a role for illness perceptions in predicting biomedical treatment outcomes and accounting for variance in physical and psychosocial adjustment across the spectrum of chronic disease (Daleboudt et al., 2013; Chilcot et al., 2011; Fortune et al., 2002; Greco et al., 2014; Griva, Myers, & Newman, 2000; Horne & Weinman, 2002; Rutter & Rutter, 2002; Schiaffino, Shawaryn, & Blum, 1998; Stafford, Berk, & Jackson, 2009; Vaughan et al., 2003). For example, Rutter and Rutter (2002) reported significant links between illness perceptions and psychosocial adjustment individuals with irritable bowel syndrome; stronger beliefs associated with illness consequence predicted lower physical and psychosocial adjustment. Similarly, Greco et al. (2014) demonstrated that illness identity predicted emotional well-being among a cohort of individuals with cardiovascular disease. Further, Daleboudt et al. (2013) identified the important role of illness perceptions in the physical functioning of individuals with systematic lupus erythematosus; stronger negative emotional perceptions related to this condition predicted poorer physical functioning related to intimate relations. Specific to biomedical treatment outcomes, Chilcot et al. (2011) reported that perceptions related to treatment control predicted survival among individuals with end-stage renal disease.

In summary, there is a wealth of evidence linking illness perceptions with biomedical treatment outcomes, physical health and psychosocial adjustment across a range of chronic health conditions (Covic, Seica, Gusbeth, Gavrilovici, & Goldsmith, 2004; Frostholm et al., 2007; Hagger & Orbell, 2003; Paddison, Alpass, & Stephens, 2008). No published research to date however, has tested these links in individuals diagnosed with HCV. The present thesis addressed this gap. The next section describes coping as a feature of the SRM, along with

research that has detailed its association with biomedical treatment outcomes, physical health and psychosocial adjustment in chronic disease conditions.

4.3 Coping and the SRM

Coping plays a significant role in predicting health related outcomes (Broadbent et al., 2006; Fitzell & Pakenham, 2010; Fowler, 2007; Kyngas et al., 2000; Pakenham, 2006). Coping has been defined as both cognitive and behavioural efforts that individuals adopt to manage internal and environmentally related stressful demands that have been appraised as exceeding normal resources (Carver & Scheier, 1983; Folkman & Lazarus, 1980; Folkman & Lazarus, 1988; Holahan & Moos, 1987; Lazarus & Folkman, 1984; Lazarus & Folkman, 1987). Chronic health conditions such as HCV can make significant demands on an individual's life (Felton & Revenson, 1987; Pierret, 2003) For example, when a chronic health condition such as HCV has an unpredictable course, or severe symptoms, an individual's coping resources or adaptive strategies can be compromised (De Ridder, Depla, Severens, & Malsh, 1997; Kyngas et al., 2000; Roesch & Weiner, 2001). Chronic health conditions such as HCV can create uncertainty, potentially disrupt daily routines, and permeate an individual's work life and personal relationships (De Ridder et al., 1997; Felton & Revenson, 1987; Kyngas et al., 2000; Pierret, 2003; Roesch & Weiner, 2001; Weinman, Wright, & Johnston, 1995). Research has suggested that stress caused by chronic health conditions can vary between individuals due in part to their perceived coping abilities (Carver, Scheier, & Weintraub, 1989; Lazarus & Folkman, 1984; Weinman et al., 1995). Early research indicated that individuals had relatively limited ways of coping with particular stressors (Weinman et al., 1995). More recent research has indicated that individuals tend to use a range of coping

behaviours to deal with different aspects of the same stressor (Carver et al., 1989; Lazarus & Folkman, 1984; Weinman et al., 1995). For example, Carver (1997) developed the Brief COPE to examine 14 different coping strategies (active coping, planning, social support, emotional support, self-blame, religion, positive re-interpretation, acceptance, venting emotions, denial, humour, behavioural disengagement, substance abuse, and self-distraction). Research has demonstrated that coping behaviours are not static, and that they can evolve and change over time. Further, environmental and personal factors such as illness perceptions can influence the choice of coping strategies (Broadbent et al., 2006; Weinman et al., 1995).

A growing body of research has confirmed the efficacy of illness perceptions to predict biomedical treatment outcomes, physical health and psychosocial adjustment across a range of chronic diseases (Chilcot et al., 2011; Daleboudt et al., 2013; De Gucht, 2015; Fortune et al., 2002; Greco et al., 2014; Miglioretti, Mazzini, Oggioni, Testa, & Monaco, 2008). In comparison, there is mixed support for coping strategies to predict physical and psychosocial adjustment outcomes. For example, Rutter and Rutter (2002) reported that coping strategies of behavioural disengagement and suppression predicted higher depression after first controlling for the contribution of illness perceptions in irritable bowel syndrome sufferers. Similarly, Helder et al. (2002) reported that coping strategies related to lower illness acceptance, greater focus on venting emotions, and behavioural and mental disengagement were all independent predictors of poorer mental health in a cohort of Huntington's disease sufferers. Scharloo et al. (2000) conducted a longitudinal study among individuals with psoriasis to investigate links between coping and biomedical, physical health and

psychosocial adjustment outcomes. At 1 year follow up, patients who adopted coping strategies associated with greater expression of emotions, higher levels of seeking social support, greater use of distraction strategies, and active coping, reported fewer psoriasis related symptoms, were less anxious and depressed, and reported better overall physical health compared to those who did not adopt such strategies (Scharloo et al., 2000). Alternatively, although Heijmans (1999) reported that illness perceptions predicted physical and psychosocial adjustment outcomes in Addison's disease, coping strategies did not add significantly to the predictive model. Similarly, in a study examining whether the SRM could account for physical and psychosocial adjustment among a cohort of individuals with atrial fibrillation, coping strategies only made minimal contributions to the prediction model after first controlling for the contribution of illness perception components (Steed et al., 1999).

Although a number of studies have demonstrated the utility of the SRM to predict both physical and psychosocial outcomes across multiple chronic diseases (Rutter & Rutter, 2002; Scharloo et al., 2000), there are more reports implicating illness perceptions than coping strategies as key variables in such relationships (Hagger & Orbell, 2003). Hagger and Orbell (2003) suggested that many coping measures used in chronic disease studies generally lack acceptable levels of specificity in relation to the particular medical condition under review. However, to date no general consensus appears to have been reached as to why illness perceptions have more consistently demonstrated the ability to predict physical and psychosocial adjustment in comparison to coping strategies within the context of chronic disease (Hagger & Orbell, 2003). The present thesis provided an opportunity to investigate the relative contributions of coping strategies to predict

treatment response, physical and psychosocial adjustment outcomes within the context of HCV, along with exploring the potential mediating role of coping in the relationship between illness perceptions and adjustment outcomes. The following section will outline the benefit finding model. A summary of research that has assessed whether benefit finding could account for variance in physical and psychosocial adjustment and biomedical treatment outcomes across a number of chronic disease conditions is provided.

4.4 Benefit Finding and HCV

Although the SRM has demonstrated links between illness perceptions, coping behaviours and health related outcomes, other research has identified associations between positive meaning, personal growth and physical and psychosocial adjustment (Helgeson et al., 2006; Leventhal et al., 1992). For example, cognitive factors such as benefit finding and meaning making have been linked to positive adjustment outcomes in chronic health conditions such as multiple sclerosis (Pakenham, 2007). Benefit finding, is also known by other related terms such as posttraumatic growth and adversarial growth, and has been described as a process where individuals find meaning in the context of adverse life events and situations, including the experience of chronic disease (Algoe & Stanton, 2009; Antoni et al., 2001; Belizzi & Blank, 2006; Cordover, Cunningham, Carlson, & Andrykowski, 2001; Fortune et al., 2005; Linley & Joseph, 2004; Pakenham, 2011; Rogan et al., 2013; Seligman & Csikszentmihalyi, 2000; Siegal & Scrimshaw, 2000; Taku et al., 2007; Thompson, 1985; Thornton & Perez, 2006; Tomich & Helgeson, 2004). Chronic illnesses such as HCV can challenge and undermine an individual's sense of meaning and perceptions about their mortality. Restoring a sense of meaning within the context of chronic illness has been linked

to positive physical and psychosocial adjustment outcomes (Littlewood et al., 2008; Lechner, Carver, Antoni, Weaver, & Phillips, 2006; Luszczynska et al., 2007; Park et al., 2009; Tennen et al., 1992). In response to adversity, examples of benefits found by individuals have included strengthened relationships, a greater appreciation of life, spiritual and personal growth, changes in life priorities and goals, changes in health behaviours, and illness acceptance (Helgeson et al., 2006; Pakenham, 2011; Stanton et al., 2006).

The ‘assumptive world theory’ developed by Janoff-Bulman (1992) provides an appropriate context for the benefit finding model. Janoff-Bulman asserts that most individuals see the world as a safe, meaningful and benevolent place. Adversarial and traumatic events, including the experience of illness, can ‘shatter’ these assumptions, potentially undermining a sense of meaning and purpose. One of the primary uses of benefit finding in the context of these ‘shattered assumptions’ is in providing a process for helping individuals to restore meaning and purpose, and order and predictability, by providing an opportunity for them to reflect on the potentially positive benefits associated with their respective crises of meaning (Janoff-Bulman, 1992; Pakenham, 2011).

One of the key assumptions associated with the benefit finding model is that an adverse event must be of sufficient perceived severity to trigger the benefit finding process (de Ridder et al., 2008). Once the benefit finding process is commenced, a number of factors can contribute to the level of individual engagement (de Ridder et al., 2008). For example, younger age, higher social status, higher severity and intensity related to the reported adverse event, and personality factors such as higher optimism, hopeful disposition, and extravert personality have been linked to higher benefit finding engagement following

adverse life events (de Ridder et al., 2008). Other factors such as socioeconomic status, educational achievement levels, and duration of the reported adverse event have less consistently been associated with benefit finding (de Ridder et al., 2008). Further, studies have not established links between gender and degree of engagement with benefit finding activities following adversity (Danoff-Burg & Revenson, 2005; de Ridder et al., 2008). Similarly, although greater illness severity been associated with more prevalent benefit finding activities, one study on breast cancer sufferers found that stronger perceptions of illness threat were linked to reduced benefit finding (Lechner et al., 2003).

To date, a number of studies have demonstrated predictive links between benefit finding and physical and psychosocial adjustment and biomedical treatment outcomes across a number of chronic illness conditions including cancer (Bower et al., 2005; McGregor et al., 2004; Park et al., 2009;), rheumatoid arthritis (Danoff-Burg & Revenson, 2005; Tennen et al., 1992), and human immunodeficiency virus (Littlewood et al., 2008; Luszczynska et al., 2007; Siegal & Schrimshaw, 2000). For example, Littlewood et al. (2008) reported that greater benefit finding predicted increased physical activity and decreased depression, among a group of individuals diagnosed with human immunodeficiency virus. Other studies however have produced less consistent results (Bower et al., 2005; Helgeson et al., 2006; McMillen & Fisher, 1998; Sears et al., 2003; Tomich & Helgeson, 2004). For example, Helgeson et al. (2006) investigated relationships between benefit finding and both psychosocial and physical health adjustment following traumatic life events, including the experience of chronic disease, reported that benefit finding was associated with lower depression, but was unrelated to physical health adjustment outcomes. Counterintuitively, a number of studies have identified

personal growth through benefit finding to co-exist simultaneously with more negative chronic illness related adjustment outcomes such as depression, physical pain and lowered physical functioning (McMillen & Fisher, 1998; Tomich & Helgeson, 2004). McMillen and Fisher (1998) commented that their results show the potential for individuals to discover benefits in the midst of adversity whilst struggling at the same time with depression. The present thesis examined these relationships within the context of HCV.

Research to date has not examined relationships of features of the SRM, i.e., illness perceptions and coping strategies, and benefit finding to physical and psychosocial adjustment and biomedical treatment response among individuals with HCV. A number of studies conducted on chronic disease have shown benefit finding to predict depression (Carver & Antoni, 2004), physical functioning (Danoff-Burg & Revenson, 2005), life satisfaction, and positive affect adjustment outcomes (Bower et al., 2005). Similarly, research has also identified the role of benefit finding in predicting biomedical treatment outcomes in chronic diseases (Bower et al., 1998; de Ridder et al., 2008; McGregor et al., 2004). However, research that has focussed on the associations between benefit finding and physical and psychosocial adjustment in chronic illness has produced inconsistent findings (Helgeson et al., 2006; McMillen & Fisher, 1998; Sears et al., 2003; Tomich & Helgeson, 2004). The present thesis thus investigates the role of benefit finding to predict biomedical treatment response, physical health and psychosocial adjustment among individuals with HCV, after first accounting for the contributions of illness perceptions and coping strategies within an expanded SRM model. Additionally, the present thesis conducted tests to assess whether benefit finding mediated the relationship between illness perceptions and physical and

psychosocial adjustment within the context of an expanded SRM. Finally, a number of studies have shown that multi-item measures such as the Perceived Benefit Scale have identified at least one area of benefit following adversity across a number of related areas of chronic disease (de Ridder et al., 2008; McMillen & Fisher, 1998), hence this measure was used in the present investigation.

4.5 Summary of Limitations in the Current Literature

The preceding chapters provided an overview of HCV, introduced the SRM and benefit finding as potentially useful psychological variables for predicting treatment response and physical and psychosocial adjustment within the context of HCV. A review of existing biopsychosocial research relevant to the SRM, benefit finding, HCV, and related chronic health conditions identified the following gaps in the literature:

- (1) Few studies have focussed on the efficacy of psychological variables to predict physical and psychosocial adjustment and treatment response within the context of HCV. To date the majority of published literature has focussed on predicting HCV treatment outcomes using biomedical variables only (Shiffman et al., 2004).
- (2) A wealth of published studies have assessed the efficacy of the SRM to account for physical and psychosocial adjustment (Broadbent et al., 2015; Hagger & Orbell, 2003), and in more limited cases biomedical treatment outcomes (Chilcot et al., 2011), across a range of chronic health conditions. However, these results have been inconsistent with regards to the relative efficacy of illness perceptions in comparison to coping to contribute to these predictive models (Hagger & Orbell, 2003). Further, only a limited number of studies have shown coping to mediate the relationship between illness perceptions and health related outcomes (Hagger & Orbell, 2003; Rutter & Rutter, 2002). To date, no published literature has

investigated whether components of the SRM predict physical and psychosocial adjustment or treatment response after controlling for demographic, clinical and behavioural co-variables among individuals with HCV.

(3) A number of studies have assessed whether benefit finding could account for variance in physical and psychosocial adjustment and biomedical treatment outcomes across a number of chronic disease conditions (de Ridder et al., 2008; Helgeson et al., 2006; McMillen & Fisher, 1998). To date, these studies have reported inconsistent or counter-intuitive results (de Ridder et al., 2008; McMillen & Fisher, 1998). No published research has determined whether benefit finding predicts physical and psychosocial adjustment and treatment response after controlling for demographic, clinical and behavioural variables in HCV. Further, no studies to date have assessed whether benefit finding mediates the relationship between illness perceptions and physical and psychosocial adjustment outcomes in HCV.

(4) There is currently no evidence to confirm whether illness perceptions, coping, and benefit finding, predict physical and psychosocial adjustment or predict treatment response after controlling for demographic, clinical and behavioural co-variables among individuals with HCV.

(5) No published literature has specifically assessed the efficacy of the following physical and psychosocial variables; physical health, depression, life satisfaction, and positive affect to predict HCV treatment response after controlling for clinical, demographic, and behavioural covariates.

4.6 Aims of the Present Thesis

Gaps in the literature confirm the need to investigate the efficacy of the traditional SRM (i.e., illness perceptions and coping), as well as benefit finding, to predict treatment response, physical health and psychosocial adjustment among individuals diagnosed with HCV. The research reported here also determined whether physical health and psychosocial adjustment predicted HCV treatment response after controlling for relevant demographic, clinical and behavioural variables (Chen & Morgan, 2006; Lee & Abdo, 2003; Shiffman et al., 2004).

Study 1.1 and Study 1.2 employed a cross-sectional design to assess whether an expanded SRM (including illness perceptions, coping strategies, and benefit finding) accounted for variance in physical health and psychosocial adjustment (depression, life satisfaction, positive affect). Study 1.1 employed the traditional order of entry as outlined by Leventhal et al. (1992). Illness perceptions were entered at Step 1 coping strategies at Step 2, and benefit finding at Step 3. Study 1.1 also investigated whether coping strategies and benefit finding mediated the relationships between illness perceptions and HCV physical and psychosocial adjustment. Study 1.2 determined whether coping strategies independently predicted HCV physical and psychosocial adjustment before variance in illness perceptions was accounted for (Heijmans, 1999). Accordingly, the traditional SRM order of entry was reversed to confirm which features were more robust predictors of physical and psychosocial adjustment.

For Study 1.1 and Study 1.2, illness perceptions were measured by the Brief Illness Perception Questionnaire (BIPQ), coping strategies by the Brief COPE, and benefit finding by the Perceived Benefits Scale (PBS) (Broadbent et al., 2006; Carver, 1997; McMillen & Fisher, 1998). The BIPQ has been used in

related chronic disease studies (Broadbent et al., 2015), and one of the measure's advantages over other measures of cognitive appraisal is that it allows a multiple individual illness perception components to be measured independently (Broadbent et al., 2006). The Brief COPE has been used in a number of studies to assess the efficacy of the SRM to account for variance in physical and psychosocial adjustment in chronic disease (Hagger & Orbell, 2003). The Brief COPE was chosen for the present study due to its ability to determine multiple coping strategies, and employ categorical groupings (i.e. adaptive and maladaptive coping) (Hagger & Orbell, 2003; Rogan et al., 2013; Rutter & Rutter, 2002). The PBS was selected as it has been used to predict psychosocial adjustment in previous chronic disease work. The measure is also easily modified for specific illnesses, including HCV (McMillen & Fisher, 1998).

To allow direct comparison between HCV and other chronic diseases a measure of physical health (Heijmans, 1999; Steed et al., 1999) and indices of depression (Fortune et al., 2002; Vaughan et al., 2003), life satisfaction (De Gucht, 2015; Rutter & Rutter, 2002), and positive affect (de Ridder et al., 2008) , served as the criterion variables for Study 1.1 and Study 1.2. Physical health has been utilised in a number of chronic disease studies that have assessed the efficacy of the SRM to predict adjustment outcomes (Heijmans, 1999; Helder et al., 2002; Rutter & Rutter, 2002). Life satisfaction (Gucht, 2015; Rutter & Rutter, 2002; Steed et al., 1999), depression (Hagger & Orbell, 2003) and positive affect (de Ridder et al., 2008) were selected as a cognitive quality of life measures that have been used in multiple chronic disease studies. The use of these criterion measures permitted direct comparison between the cognitive characteristics of HCV and other manifestations of chronic illness.

Symptoms associated with depression were measured using the depression subscale of the Depression, Anxiety and Stress Scales (DASS-21: Lovibond & Lovibond, 1995). The DASS-21 has been used to evaluate reported depression within chronic disease populations in other studies (e.g., Covic et al., 2011). Importantly, the DASS-21 depression sub-scale items focus more on the cognitive and affective features of depression rather than somatic features such as insomnia, appetite, fatigue and concentration, which can also be potential medical symptoms related to chronic disease conditions rather than mood related causes (Covic et al., 2011; Lovibond & Lovibond, 1995). Physical health was measured by the physical summary component of the RAND 36-item Health Survey 1.0 questionnaire (RAND-36) (Covic et al., 2004; VanderZee, Sanderman, Heyink, & de Haes, 1996). Apart from minor differences in scoring, the RAND-36 is identical to the physical health items of the MOS 36-item Short-Form Health Survey (SF-36) which has been utilised in previous chronic disease studies (Brazier et al., 1992; Hagger & Orbell, 2003). A particular strength relevant to the use of the RAND-36 in the present thesis is the inventory's ability to measure health related quality of life across a number of dimensions of physical health including physical functioning, role functioning (physical), bodily pain, and general health perceptions (Brazier et al., 1992; Covic et al., 2004; VanderZee et al., 1996), which fits well with the range of physical symptoms experienced by individuals with HCV. The five-item Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985) and the Bradburn Affect Balance Scale (BABS) (Bradburn, 1969) were used to measure psychosocial quality of life. Both the Satisfaction with Life Scale and the BABS have been utilised as measures of adjustment in other chronic disease studies (Heckman, 2003; Nabi, Kivimaki, Vogli, Marmot, & Singh-

Manoux, 2008), and both measures appear to have high face validity related to the psychosocial quality of life constructs measured (Bradburn, 1969; Diener et al., 1995).

Pre-treatment illness perceptions, benefit finding, and coping strategies have shown to account for variance in biomedical health outcomes following treatment across a number of chronic disease studies (Broadbent et al., 2015; Chilcot et al., 2011; de Ridder et al., 2008; Hagger & Orbell, 2003; Helgeson et al., 2006; McMillen & Fisher, 2008). At this time however, no published studies have determined whether illness perceptions, coping and benefit finding (i.e., an expanded SRM) at pre-treatment could predict HCV treatment response after first controlling for important demographic, behavioural and clinical variables at pre-treatment (Chen & Morgan, 2006; Lee & Abdo, 2003; Shiffman et al., 2004). Therefore, using a longitudinal design for each of the following three analyses, Study 2.1 investigated whether the traditional features of the SRM (i.e., illness perceptions and coping strategies) at pre-treatment predicted HCV treatment response, whilst Study 2.2 determined whether an expanded SRM that included benefit finding predicted HCV treatment response. Treatment response measured at Time 2 assessed whether (1) HCV was detected following a series of milestone blood tests (non-response) or (2) not detected (treatment response). This method for assessing HCV treatment response has been used in a number of previous biomedical studies (Chen & Morgan, 2006; Lee & Abdo, 2003; Shiffman et al., 2004). Finally, Study 2.3 investigated the efficacy of the criterion variables used in Study 1.1 and Study 1.2 (depression, physical health, life satisfaction and positive affect), to predict HCV treatment response after controlling for the same

demographic, behavioural and clinical variables that demonstrated significant relationships with HCV treatment response reported in Study 2.1 and Study 2.2.

Chapter 5

General Method

5.1 Participants

A sample of 126 individuals (68 males and 58 females) completed the pre-treatment (Time 1) survey ($M = 41.6$ years; $SD = 11.9$). Out of this cohort, 32 participants (13 males and 19 females; $M = 43.3$ years; $SD = 13.5$) completed the post-commencement of HCV treatment (Time 2) survey. Inclusion criteria included a current HCV diagnosis, being at least 18 years of age (HCV treatment is not available to individuals under the age of 18), access to the internet, and a current e-mail address. Ethical approval and informed consent were obtained prior to data collection.

5.2 Biomedical, Clinical, Behavioural and Demographic Information (Time 1)

At Time 1, participants responded to specific questions related to age, body weight, HCV genotype, gender, and most likely route of HCV infection. They also provided yes/no responses to the following socio-demographic and clinical questions: (1) *“Did the liver biopsy or scan results indicate the presence of cirrhosis of the liver?”* (2) *“Do you have any other medical conditions that you are currently receiving treatment for?”* (3) *“In the past week, have you used recreational drugs?”* (4) *“In the past week, have you consumed any alcohol?”* (5) *“In the past week, have you smoked any cigarettes?”* (6) *“Do you have any mental health condition/s that you are currently receiving medication based treatment for?”* (e.g., depression/anxiety/psychosis), and (7) *“Have you ever had previous treatment for Hepatitis C?”*

5.3 Illness Perceptions

Illness perceptions were measured using the Brief Illness Perception Questionnaire (BIPQ: Broadbent et al., 2006). The BIPQ is a nine-item measure that has been used across a range of chronic illness conditions and has demonstrated sound psychometric properties (Broadbent et al., 2015). The BIPQ is a shorter version of the earlier 84-item Illness Perceptions Questionnaire – Revised (IPQ-R: Broadbent et al., 2006). The BIPQ has demonstrated acceptable associations with the IPQ-R across all of the equivalent illness perception components (Broadbent et al., 2006). The BIPQ has eight items that focus on the measurement of illness perceptions (a ninth item that assesses causality using an open ended question was not included in the present study), each of which is rated on an 11-point Likert scale. Scores on each item range between 0 and 10. Higher scores reflect a greater endorsement of the given perception (e.g., higher scores indicate a greater illness understanding, higher negative illness impact, and more severe illness symptoms). For each of the BIPQ items, the word ‘illness’ was replaced by ‘HCV’. Each of the eight BIPQ items was as follows: (1) “*How much does your HCV affect your life?*” (illness consequences), (2) “*How long do you think your HCV will continue?*” (illness timeline), (3) “*How much control do you feel you have over your HCV?*” (personal control), (4) “*How much do you think your treatment can help your HCV?*” (treatment control), (5) “*How much do you experience symptoms from your HCV?*” (illness identity), (6) “*How concerned are you about your HCV?*” (illness concern), (7) “*How well do you feel you understand your HCV?*” (illness understanding or coherence), and (8) “*How much does your HCV affect you emotionally? (e.g., does it make you angry, scared, upset or depressed?)*”, (emotional response) (Broadbent et al., 2006). Consistent with the

majority of research that has utilised the BIPQ, scoring was performed at an individual item level, with five items measuring cognitive illness representations (illness consequences, timeline, personal control, treatment control, and identity), two items measuring emotional representations (concern and emotions), and one item measuring illness understanding (Broadbent et al., 2015; Hagger & Orbell, 2003). Higher scores on the illness consequence, timeline, identity, concern and emotions subscales are indicative of more negative or threatening illness perceptions. Conversely, higher scores on the personal control, treatment control and illness understanding subscales indicate more positive illness related perceptions. The BIPQ has shown good test-retest reliability and concurrent validity along with good predictive and discriminant validity (Broadbent et al., 2006). In the present study, Cronbach's alpha for the BIPQ was .69.

5.4 Coping

Coping was measured by the Brief COPE (Carver, 1997), which is a short 28-item version of the original 60-item COPE measure. Sample items include "I take action to try to make the situation better" and "I blame myself for the things that happened". Individuals rate both items for each of the 14 subscales from 1 (*don't do this at all*) to 4 (*do this a lot*). Scores for each subscale range from 2 to 8. Higher scores on individual subscales indicate the extent to which each coping strategy was used (Carver et al., 1989; Weinman, Wright, & Johnston, 1995). Following Rogan, Fortune, and Prentice (2013), coping strategies for the present study were divided into adaptive (mental disengagement, active coping, use of emotional support, use of instrumental support, positive reframing, planning, use of humour, acceptance and use of religion), and maladaptive (denial, substance use, venting, self-blame and behavioural disengagement) subscales (Carver, 1997;

Rogan et al., 2013). Both the adaptive (Cronbach's $\alpha = .57$ to $.82$) and maladaptive (Cronbach's $\alpha = .50$ to $.90$) subscales have achieved acceptable internal consistency values in previous research (Carver, 1997; Cooper, Katona, & Livingston, 2008; Rogan et al., 2013). In the present study, excellent internal consistency coefficients were obtained for the adaptive (Cronbach's $\alpha = .90$), and maladaptive (Cronbach's $\alpha = .86$) coping strategies.

5.5 Benefit Finding

Benefit finding was measured by the Perceived Benefits Scale (PBS: McMillen & Fisher, 1998). The PBS has 38 items of which 30 reflect benefits since diagnosis. The measure includes 8 items reflecting negative changes, and in accord with the scoring procedures, responses to these items were excluded from analyses (McMillen & Fisher, 1998). Participants were asked to indicate how well “each statement describes your experience” on a five-point Likert scale ranging from 0 (*not at all like my experience*) to 4 (*very much like my experience*). Sample items from the PBS include “Because of this illness, I have learned how good people can be” and “This illness has made me a stronger person” (McMillan & Fisher, 1998). Higher scores on the PBS reflect higher levels of positive benefit finding. The PBS has shown good test-retest reliability and concurrent validity along with good predictive and discriminant validity (McMillan & Fisher, 1998; Park et al., 2009). A Cronbach alpha of $.96$ was obtained for the present study.

5.6 Depression

Mental health was measured by the depression subscale of the Depression, Anxiety and Stress Scales (DASS-21: Lovibond & Lovibond, 1995). The DASS-21 is a 21-item short form version of the 42-item self-report DASS. The seven-item depression subscale requires respondents to rate the extent to which he or she

experienced each symptom over the past week on a 4-point Likert scale (0 = *did not apply to me at all* to 3 = *applied to me very much or most of the time*). Sample items from the depression subscale include “I couldn’t seem to experience any positive feeling at all” and “I felt that life was meaningless”. To provide equivalence of scoring with the longer version of the DASS, a total score was created by summing all items within the subscale and then multiplying the total score by two. (Lovibond & Lovibond, 1995; Miller et al., 2006). Scores for the Depression subscale range from 0 to 42, with higher scores indicative of greater depression (Lovibond & Lovibond, 1995; Miller et al., 2006). The DASS-21 depression subscale has demonstrated a high internal consistency of Cronbach’s $\alpha = .92$ (Lovibond & Lovibond, 1995), in addition to adequate construct, convergent, and discriminant validity (Clara, Cox, & Enns, 2001; Henry & Crawford, 2005; Lovibond & Lovibond, 1995; Miller et al., 2006). In the present study, the DASS-21 demonstrated strong internal consistency (Cronbach’s $\alpha = .91$).

5.7 Life Satisfaction

The five-item Satisfaction with Life Scale (SLS; Diener, Emmons, Larsen, & Griffin, 1985) was used to measure life satisfaction. Participants rated each item from 1 (*strongly disagree*) to 7 (*strongly agree*). Possible scores ranged from 0 to 35, with higher scores indicative of greater life satisfaction. Sample statements from the SLS include “In most ways, my life is close to ideal” and “I am satisfied with my life” (Diener et al., 1985). The SLS has demonstrated good internal consistency (Cronbach’s $\alpha = .87$) in previous research (Diener et al., 1985; Pavot & Diener, 1993). Similarly, the scale demonstrated strong internal consistency in the present study (Cronbach’s $\alpha = .90$). The SLS has also

demonstrated sound convergent validity with similar measures of subjective well-being (Diener et al., 1985; Pavot & Diener, 1993).

5.8 Positive Affect

Positive affect was measured by the Bradburn Affect Balance Scale (BABS) (Bradburn, 1969). The BABS is a 10-item rating scale containing five statements reflecting positive feelings and five statements reflecting negative feelings (Bradburn, 1969). Only the five positive items of the BABS were utilised in the present thesis. Participants indicate on a 5-point scale from 1 (*not at all*) to 5 (*very often*) how relevant each of the statements was to them over the past few weeks (Bradburn, 1969; van Schuur & Kruijtbosch, 1995). For the five positive statements, scale scores range from 5 to 25 with higher scores indicating better adjustment. Sample statements include “Particularly excited or interested in something” and “That things were going your way”. Overall, the BABS has demonstrated sound psychometric properties in terms of acceptable reliability in both clinical and non-clinical samples (e.g., Cronbach’s $\alpha = .94$; Pakenham & Cox, 2008). The BABS demonstrated strong internal consistency in the present study (Cronbach’s $\alpha = .88$).

5.9 Physical Health

The physical summary component of the RAND 36-item Health Survey 1.0 questionnaire (RAND-36) was used to measure aspects of physical health (Covic, Seica, Gusbeth-Tatomir, Gavrilovici, & Goldsmith, 2004; VanderZee, Sanderman, Heyink, & de Haes, 1996). The physical summary component of the RAND-36 measures physical health status based on the subjective self-reports across four dimensions: physical functioning, role limitations related to physical health issues, bodily pain, and general health (Brazier et al., 1992; Covic et al., 2004; VanderZee

et al., 1996). For example, the physical functioning subscale measures perceptions of physical functioning as a component of general health status. Individuals respond to the following question “Does your health now limit you in these activities? If so, how much?” Activities covered include “running”, “walking”, “carrying groceries”, and “bathing and dressing”. Items are rated on a three point Likert scale ranging from 1 (*Yes, Limited a Lot*) to 3 (*No, Not Limited at All*). Total scores for each subscale range from 0 to 100, with higher scores indicating better physical functioning and more positive health perceptions (Brazier et al., 1992; Covic et al., 2004; Ngo-Metzger, Sorkin, Mangione, Gandek, & Hays, 2008; VanderZee et al., 1996). Apart from some differences related to scoring methods, the RAND -36 is identical to the items of the MOS 36-item Short-Form Health Survey (SF-36) which has achieved good internal consistency (Cronbach’s $\alpha = .85$) (Brazier et al., 1992). In the present study the RAND-36 achieved acceptable internal consistency (Cronbach’s $\alpha = .78$).

5.10 HCV Treatment Outcome Assessment and Adherence (Time 2)

HCV treatment response was the outcome measure evaluated at Time 2 (3 months post commencement of HCV treatment). At Time 2, participants were asked to indicate what blood tests (known as polymerase chain reaction (PCR) tests) they had since commencing HCV treatment, and to indicate the outcome for each test. Three questions covered week four, week eight, and week twelve PCR blood tests respectively. For each question, participants were asked to indicate either (1) ‘Hepatitis C virus was detected in my blood’ or (2) ‘Hepatitis C virus was not detected in my blood’. A response indicating nil detection of HCV for at least one of the three milestone PCR blood tests was recorded as a ‘treatment

response' result for future statistical analysis. Additionally, the Time 2 survey asked participants to make a yes/no response to the following treatment adherence question: *“In reference to taking your Hepatitis C medication since commencing treatment; during the first 12 weeks of treatment, did you take your medication as prescribed?”*

5.11 Procedure

A number of recruitment strategies were utilised, including internet-based advertising methods (e.g., contacting Hepatitis C peak body websites across Australia), and traditional hard-copy advertising flyers mailed to the residences of individuals preparing for HCV treatment at the Gold Coast University Hospital liver clinic. Data was collected over 22 months.

Volunteers were directed to the study website. After providing informed consent they were given a unique personal login identifier and password that granted access to the Time 1 anonymous online pre-treatment questionnaires. Relevant information was also collected to illustrate key socio-demographic and medical characteristics of the cohort. Completion of the Time 1 survey took between 30 and 40 minutes per person. Participants were contacted three months post commencement of HCV treatment and were invited to complete a second online survey questionnaire (Time 2). At Time 2 participants responded to questions related to HCV treatment outcome, and to treatment adherence relevant to the treatment period. The Time 2 online survey took between 5 and 10 minutes to complete.

Chapter 6

Study 1.1 - Illness Perceptions, Coping, Benefit Finding, and Adjustment in Hepatitis C

6.1 Introduction

As previously described in chapter 2, HCV is a chronic blood borne illness associated with significant physical and psychological difficulties, and is the leading cause of liver morbidity and mortality in the world (Chen & Morgan, 2006; Zimmer, Schiedermaier, & Grandt, 2004; Lee & Abdo, 2003; Lee & Harrison, 2005; Shiffman et al., 2004; Simmonds, 2001). Estimates suggest that approximately 170 million individuals worldwide live with chronic HCV, but despite the availability of a potential treatment cure, only a small percentage undergo anti-viral treatment (Lee & Abdo, 2003; Shiffman et al., 2004). To improve biomedical treatment outcomes for individuals who do undertake treatment, a wealth of studies have assessed whether a range of biomedical markers could predict HCV treatment response (Lee & Abdo, 2003; Shiffman et al., 2004). However, in comparison, little research has been conducted that has focused on the efficacy of psychological variables to account for variance in physical (perceptions related to general health and physical functioning) and psychosocial (psychological well-being) adjustment among individuals with HCV (Hagger & Orbell, 2003).

As previously outlined in chapter 4, Leventhal et al. (1992) developed a psychological framework, the SRM, to explain the links between cognitive and emotional representations of illness, coping behaviours and health related outcomes (Leventhal et al., 1992; Rogan et al., 2013). The SRM suggests that on becoming aware of an illness threat, individuals respond by constructing illness perceptions which form the basis for subsequent health related coping behaviours

(Leventhal et al., 1992). Illness perceptions and coping behaviours are linked to health related outcomes within a continuous feedback loop, where both illness perceptions and coping behaviours are adjusted in response to health related outcomes (Broadbent, Petrie, Main, & Weinman, 2006;. Lau & Hartman, 1983; Leventhal et al., 1992).

A number of studies have investigated the efficacy of the SRM to predict both physical and psychosocial adjustment, and in a limited number of studies, biomedical treatment outcomes (Chilcot, Wellsted, & Farrington, 2011; Hagger & Orbell, 2003) across a range of chronic diseases. For example, Paddison et al. (2008) investigated the relationships between illness perceptions and physical and psychosocial outcomes among a cohort of individuals with Type 2 diabetes. In this study, illness perceptions accounted for significant variance in metabolic control and reported quality of life. Within the context of chronic disease, illness perceptions have consistently predicted variance in both physical and psychosocial adjustment (Fortune et al., 2002; Heijmans, 1999; Rutter & Rutter, 2002; Scharloo et al., 2000; Steed, Newman, & Hardman, 1999; Vaughan et al., 2003). For example, Vaughan et al. (2003) conducted a study investigating whether illness perceptions was linked to adjustment in individuals diagnosed with multiple sclerosis. Results indicated that illness perceptions predicted physical and psychosocial adjustment outcomes, including reported illness intrusiveness, physical functioning, depression, anxiety, and self-esteem (Vaughan et al., 2003). However, coping strategies have produced less consistent results, with a number of studies demonstrating significant predictive ability related to physical and psychosocial adjustment outcomes (Helder et al., 2002; Rutter & Rutter, 2002), whereas other studies have not demonstrated the same predictive ability (Steed et

al., 1999). For example, in a study conducted among individuals diagnosed with Huntington's disease, both illness perceptions and coping strategies made significant contributions to physical and psychosocial adjustment (Helder et al., 2002). In contrast, Steed et al. (1999) conducted a study to investigate whether illness perceptions and coping could predict psychosocial adjustment among a cohort of individuals with atrial fibrillation. Results identified a significant role for illness perceptions in contributing to psychosocial adjustment outcomes, but not for coping (Steed et al., 1999). A number of potential factors may have contributed to the less consistent role of coping to predict adjustment in comparison to illness perceptions as reported across a number of health related studies (Hagger & Orbell, 2003). For example, it may be that different coping measures used across a number of studies in comparison to the more consistent use of illness perception measures may have contributed to variance in the ability of coping to predict adjustment (Hagger & Orbell, 2003). The present thesis provided an opportunity to test the efficacy of illness perceptions and coping, original features of Leventhal's et al. (1980) SRM within the novel area of HCV.

Leventhal et al. (1980) proposed a mediational role for coping strategies within the SRM. Leventhal et al. hypothesised that coping strategies would mediate the relationship between illness perception components and health related outcomes. To date, the majority of SRM studies have not identified a role for coping in mediating the relationship between illness perceptions and health related outcomes (Hagger & Orbell, 2003; Heijmans, 1998; Kemp et al., 1999; Moss-Morris et al., 1996; Scharloo et al., 1998). For example, Scharloo et al. (1998) assessed the potential for coping strategies to mediate the relationship between illness perceptions and physical and psychosocial adjustment among individuals

diagnosed with either rheumatoid arthritis, chronic obstructive lung disease, or psoriasis. The findings of this study indicated that coping did not demonstrate a mediating role between illness perceptions and adjustment. Further, coping did not account for significant variance across any of the criterion variables. In comparison, illness perceptions demonstrated significant contributions to the predictive models regardless of their entry into the regression models (Scharloo et al., 1998). In a limited number of related studies, coping has mediated the relationship between illness perceptions and health related outcomes (Rutter & Rutter, 2002). For example, Rutter and Rutter (2002) demonstrated a role for coping in mediating some, but not all of the relations between illness perceptions and adjustment outcomes. Specifically, the following coping strategies; (1) acceptance, (2) active coping, (3) venting emotions, and (4) behavioural disengagement, demonstrated utility in mediating links between illness perception components and adjustment outcomes (Rutter & Rutter, 2002).

No published studies have assessed whether coping strategies could mediate the relationships between illness perceptions and physical and psychosocial adjustment within the context of HCV. The approach reported here will allow comparison with results of mediation tests conducted across other chronic disease areas, and some of the inconsistencies reported to date regarding the role of coping as a mediator between illness perceptions and health related outcomes within the spectrum of chronic disease (Leventhal et al., 1980).

Important to the present thesis, other psychological models have identified associations between positive meaning, personal growth, and physical and psychosocial adjustment (Helgeson, Reynolds, & Tomich, 2006; Leventhal et al., 1992). For example, cognitive factors such as benefit finding have been linked to

physical and psychosocial adjustment outcomes across a range of chronic health conditions (Helgeson et al., 2006). Benefit finding has been described as a process where individuals find meaning in the context of adverse life events and situations, including the experience of chronic disease (Fortune, Richards, Griffiths, & Main, 2005; Pakenham, 2007; Pakenham, 2011; Rogan, Fortune, & Prentice, 2013; Seligman & Csikszentmihalyi, 2000; Siegal & Scrimshaw, 2000; Thompson, 1985). In response to adversity, examples of benefits found by individuals have included strengthened relationships, a greater appreciation of life, spiritual and personal growth, changes in life priorities and goals, changes in health behaviours, and illness acceptance (Helgeson et al., 2006; Pakenham, 2011; Stanton, Bower, & Low, 2006).

A number of studies have demonstrated predictive links between benefit finding and physical and psychosocial adjustment within the context of chronic disease (Littlewood, Vanable, Carey, & Blair, 2008; Luszczynska, Sarkar, & Knoll, 2007; Park, Chmielewski, & Blank, 2009; Tennen, Affleck, Urrows, Higgins, & Mendola, 1992). Other studies have produced less consistent results (Helgeson et al., 2006; McMillen & Fisher, 1998; Sears, Stanton, & Danoff-Burg, 2003; Tomich & Helgeson, 2004). For example, Bower et al. (2005) investigated whether benefit finding accounted for variance in psychosocial adjustment among a cohort of breast cancer survivors. Results indicated that benefit finding was associated with positive affect measured at time periods between 1–10 years post diagnosis. However, in a related study, benefit finding measured at four months post diagnosis of breast cancer was not associated with positive affect (Tomich & Helgeson, 2004). Further, Danoff-Burg and Revenson (2005) conducted a longitudinal study to investigate whether benefit finding predicted adjustment

outcomes among a group of individuals living with rheumatoid arthritis. The majority of individuals who participated in this study (71.3%) reported the discovery of at least one interpersonal benefit related to their chronic condition. At 12 months follow up the data indicated that benefit finding predicted lower reported physical disability among this group of individuals. Other studies have produced more counter-intuitive results where benefit finding has co-existed simultaneously with more negative adjustment outcomes such as depression and reduced physical functioning (de Ridder et al., 2008; McMillen & Fisher, 1998; Tomich & Helgeson, 2004). However, these results may indicate that the ability to find meaning following an adverse event can occur simultaneously with lower mood (McMillen & Fisher, 1998).

Several ideas have been offered to account for the inconsistent findings associated with the role of benefit finding in predicting physical and psychosocial adjustment among individuals living with chronic disease. For example, the measurement of benefit finding at relatively shorter time periods after initial diagnosis has generally been associated with lower benefit finding (de Ridder et al., 2008; Helgeson et al., 2006; McMillen & Fisher, 1998), whereas longer time intervals have been associated with higher benefit finding and more favourable physical and psychosocial adjustment (de Ridder et al., 2008; Helgeson et al., 2006; McMillen & Fisher, 1998). Additionally, other factors related to personality differences, severity of illness experience and whether benefit finding interventions were provided to individuals living with chronic disease have been linked to variance in findings reported in benefit finding literature (de Ridder et al., 2008; Helgeson et al., 2006; McMillen & Fisher, 1998). Specifically, more optimistic personality types, greater illness severity and benefit finding interventions have

been linked to greater benefit finding ability and improved adjustment (De Ridder et al., 2008; Helgeson et al., 2006; McMillen & Fisher, 1998). Overall, Benefit finding has demonstrated an important role in predicting physical and psychosocial adjustment across a number of chronic disease conditions (de Ridder et al., 2008; Helgeson et al., 2006). Further, providing opportunities for individuals to discover positive meaning in response to their illness experience has been associated with a greater potential for improved illness related adjustment (de Ridder et al., 2008; Helgeson et al., 2006). Including the investigation of links between benefit finding and adjustment in the present study will provide an opportunity to assess the relative importance of benefit finding within the context of adjustment to HCV. Further, benefit finding would be activated following initial awareness of various illness threats and the subsequent formation of illness perceptions, and therefore provides an additional opportunity to explore whether it mediates the relationships between illness perceptions and adjustment outcomes. (de Ridder et al., 2008; Hagger & Orbell, 2003; Helgeson et al., 2006).

Research to date has not examined relationships between traditional features of the SRM, benefit finding and physical and psychosocial adjustment among individuals with HCV. Therefore, the primary aim of Study 1.1 was to investigate whether features of an expanded SRM, would predict physical and psychosocial adjustment outcomes. A secondary aim was to test if coping strategies and benefit finding mediated the relationships between illness perception components and health related outcomes. The potential for benefit finding to demonstrate a mediational role between illness perceptions and health related outcomes has not been investigated in any other published chronic disease studies.

Illness perceptions, adaptive and maladaptive coping strategies were expected to predict physical health, life satisfaction, and positive and negative mood adjustment outcomes. Benefit finding was also expected to make significant contributions to the predictive model after controlling for the combined contributions of the SRM features, illness perceptions, and adaptive and maladaptive coping. Finally, both coping strategies and benefit finding were expected to mediate the relationships between illness perceptions and physical and psychosocial adjustment outcomes across a number, but not all of the predictors.

6.2 Methods

Study 1.1 was provided research ethics approval by both the Bond University Human Research Ethics Committee, and the Gold Coast Hospital and Health Service Human Research Ethics Committee. Both ethics committees are located in the state of Queensland, Australia.

6.2.1 Participants

There were 126 individuals with HCV who were recruited for Study 1.1. Inclusion criteria included a current HCV diagnosis, at least 18 years of age (HCV treatment is not available to individuals under the age of 18), access to the internet, and a current e-mail address. Table 6.1 summarises clinical, behavioural and demographic information.

Table 6.1

Sample Characteristics ($N = 126$)

Characteristic	<i>N</i>	(%)	<i>M</i>	<i>SD</i>
Age			41.6	11.9
Gender				
Male	68	54.0		

Female	58	46.0
Liver cirrhosis ($n = 86$)	29	33.7
Medical co-morbidity	49	38.9
Recreational drug use ($n = 121$)	41	33.9
Alcohol consumption	38	30.2
Nicotine dependence	40	31.7

6.2.2 Measures

Illness perceptions

Illness perceptions were measured using the Brief Illness Perception Questionnaire (BIPQ: Broadbent et al., 2006). The psychometric properties of the measure are described in Chapter 5.

Coping

Coping was measured by the Brief COPE (Carver, 1997). As described in chapter 5, the Brief COPE is a multidimensional coping inventory that was developed on theoretical grounds (Carver, 1997).

Benefit Finding

Benefit finding was measured by the 38-item Perceived Benefits Scale (PBS: McMillen & Fisher, 1998). The psychometric properties of the measure are described in Chapter 5.

Depression

Mental health was measured by the depression subscale of the Depression, Anxiety and Stress Scales (DASS-21; Lovibond & Lovibond, 1995). As described

in chapter 5, the DASS-21 is a 21-item short form version of the 42-item self-report DASS.

Physical health

The physical summary component of the RAND 36-item Health Survey 1.0 questionnaire (RAND-36) (Covic et al., 2004; VanderZee et al., 1996) was used to measure aspects of reported physical health related quality of life (Covic et al., 2004; VanderZee et al., 1996). As described in chapter 5, the physical summary component of the RAND-36 measures health related quality of life across four dimensions of physical health: physical functioning, role functioning (physical), bodily pain, and general health (Brazier et al., 1992; Covic et al., 2004; VanderZee et al., 1996).

Life satisfaction

The five-item Satisfaction with Life Scale (Diener et al., 1985) was used to measure life satisfaction. The psychometric properties of the measure are described in Chapter 5.

Positive Affect

Positive affect was measured by the Bradburn Affect Balance Scale (BABS) (Bradburn, 1969). As described in chapter 5, the BABS is a 10-item rating scale containing five statements reflecting positive feelings and five statements reflecting negative feelings (Bradburn, 1969). The present analysis used the five positive items of the scale. The psychometric properties of the measure are described in Chapter 5.

6.2.3 Procedure

Recruitment strategies included internet-based advertising (e.g., contacting Hepatitis C peak body websites across Australia), and traditional hard-copy

advertising flyers mailed to the residences of individuals preparing for HCV treatment at the Gold Coast University Hospital liver clinic (35 advertising flyers mailed out). Online and hard-copy advertising strategies provided background information to the present anonymous study and included a link to the study website. The website contained background information and material related to the consent process. After providing informed consent via the website, participants were provided a unique personal login identifier and password that enabled access to the anonymous online questionnaires. Completion of the online survey took between 30 and 40 minutes. There was no incentive offered to participants for completing the survey.

6.2.4 Results

Analyses were performed using the IBM Statistical Package for Social Sciences (SPSS) Version 23.0. Tests of significance were considered reliable at $p < .05$. Prior to the main tests variables were examined for accuracy of data entry, missing values, and fit between their distributions and assumptions of regression analysis. Analysis of missing values across the study variables revealed no obvious pattern and missing values were replaced by the group mean on the measure (Tabachnick & Fidell, 2001). The data were screened for normality, skewness, kurtosis, and outliers. Inspection of the Normal Probability Plots (P-P) of the Regression Standardised Residuals and Scatterplots for each of the dependent variables indicated reasonably normal distribution of the data (Tabachnik & Fidell, 2001). There were no univariate outliers (based on results for each of the independent and criterion variables; $z < 3.29$), and therefore analysis was conducted on the full data set (Tabachnik & Fidell, 2001).

Kolmogorov-Smirnov tests for normality were performed (Tabachnick & Fidell, 2001); illness consequence ($p < .001$), illness timeline ($p < .001$), personal control ($p < .001$), treatment control ($p < .001$), illness identity ($p < .001$), illness concern ($p < .001$), illness coherence ($p < .001$), emotional response ($p < .001$), adaptive coping ($p = .041$), maladaptive coping ($p = .051$), benefit finding ($p = .081$), depression ($p = .006$), positive affect ($p = .017$), life satisfaction ($p = .039$), and physical health ($p = .082$). Further, inspection of relevant histograms and normal probability plots for each of the independent and dependent variables suggested that the data were reasonably normally distributed (Tabachnick & Fidell, 2001).

Negative skewness was identified in the eight illness perception components, and in adaptive coping, benefit finding, positive affect, and life satisfaction. Positive skewness was identified in maladaptive coping, depression and physical health. The direction for each of the Skewness values across the independent and dependent variables were generally as would be expected. For example, it would be generally expected that life satisfaction data would indicate negative skewness, whereas depression would generally be expected to indicate positive skewness values. Therefore the data remained untransformed in the statistical analyses (Pallant, 2007). Descriptive data for the predictor and criterion variables are shown in Table 6.2.

A post hoc power analysis was completed using G*power statistical software (Faul, Erdfelder, Lang, & Buchner, 2007). $N = 126$ was used for the power analyses and 11 predictor variables were entered into the model. An anticipated effect size ($f^2 = .15$) was entered into the power analysis equation. A p

< .05 alpha level was used. Post hoc analyses revealed an adequate power of .82 for this study (Faul et al., 2007).

The inter-correlations between predictor variables are shown in Table 6.3. Hierarchical multiple regression analyses were used to investigate whether illness perceptions, maladaptive and adaptive coping strategies, and benefit finding predicted depression, physical health, life satisfaction, and positive affect. Entry of the predictor variables was determined based on research related to Leventhal's self-regulatory model (SRM; Leventhal et al., 1992). Therefore, for each of the four predictive models, the illness perception components were entered on Step 1, adaptive and maladaptive coping strategies were entered on Step 2, and benefit finding was entered at Step 3. The unstandardised coefficients, beta weights, and confidence intervals for all variables and tests are shown in Table 6.4.

Based on mediation theory as outlined by Baron and Kenny (1986), a number of standard regression and hierarchical regression tests were conducted to assess the ability of (1) coping to mediate the relationship between illness perception components and study criterion variables, and (2) benefit finding to mediate the relationship between illness perception components and physical and psychosocial adjustment outcomes. Only the illness perception components, coping strategies and benefit finding predictor variables that demonstrated significant predictive links with criterion variables in earlier hierarchical regression analyses (refer to Table 6.4) were included in subsequent tests of mediation. Sobel tests were utilised to evaluate whether mediation had been established following tests to measure predictive links between illness perception items and criterion variables, and tests to measure predictive links between illness perception components and respective mediator variables (Preacher & Hayes, 2004).

Table 6.2

Descriptive Statistics for Predictor and Criterion Variables ($N = 126$)

Variables	<i>Mean</i>	<i>SD</i>	<i>Range</i>
Illness consequences	5.8	2.6	0 – 10
Illness timeline	6.0	2.6	0 – 10
Personal control	5.2	2.7	0 – 10
Treatment control	7.1	2.1	0 – 10
Illness identity	5.4	2.6	0 – 10
Illness concern	7.0	2.4	0 – 10
Illness coherence	6.5	2.4	0 – 10
Emotional response	5.8	2.8	0 – 10
Adaptive Coping	46.9	10.2	18 – 72
Maladaptive Coping	20.0	6.4	10 – 40
Benefit Finding	60.6	25.8	0 – 120
Depression	16.5	11.0	0 – 42
Physical Health	52.7	20.9	0 – 100
Life Satisfaction	19.5	7.1	5 – 35
Positive Affect	15.0	4.1	5 – 25

Table 6.3
Inter-correlations among Study Predictors.

	1	2	3	4	5	6	7	8	9	10
1. Illness consequence										
2. Illness timeline	.43**									
3. Personal control	.07	-.01								
4. Treatment control	.08	-.20*	.27**							
5. Illness identity	.56**	.28**	.16	.06						
6. Illness concern	.48**	.33**	-.10	.05	.44**					
7. Illness coherence	.07	-.05	.28**	.35**	.11	-.02				
8. Emotional response	.69**	.34**	-.01	.10	.52**	.49**	.11			
9. Maladaptive coping	.27**	.16	.07	-.03	.19*	.04	-.11	.37**		
10. Adaptive coping	.11	.13	.12	.23*	.09	.07	.27	.18*	.38**	
11. Benefit Finding	.23*	-.02	.38**	.11	.34**	.06	.17	.18*	.23*	.34**

Note. * $p < .05$ ** $p < .01$

Predictors of Depression

There were a number of significant zero-order correlations among illness perception components, coping strategies, benefit finding and depression scores. Greater illness consequence ($r = .38$), longer illness duration ($r = .29$), greater identification with illness related symptoms ($r = .39$), higher levels of illness concern ($r = .25$), and higher emotional responses to HCV ($r = .47$) were associated with higher depression. Conversely, higher personal control ($r = -.18$) and greater illness understanding ($r = -.18$) were associated with lower depression. Both adaptive coping ($r = .16$) and maladaptive coping ($r = .53$) were significantly

and positively associated with depression. Similarly, benefit finding ($r = .27$) was significantly and positively associated with depression.

At Step 1, the model was significant, $F(8, 117) = 8.02, p < .001$, and the illness perceptions accounted for 35% of the variance in depression scores, $R = .60$, $F(8, 117) = 8.02, p < .001$. Increased perceptions related to personal control (2%; $\beta = .17, t = 2.04, p = .043$) and illness coherence (3%; $\beta = -.18, t = 2.22, p = .028$) were significant unique predictors of lower depression, whereas higher HCV illness identity (4%; $\beta = .25, t = 2.61, p = .010$) and greater emotional responses (6%; $\beta = .35, t = 3.26, p = .001$) predicted higher depression. At Step 2, the model accounted for 48% of the variance in depression scores and after controlling for the illness perception components the combined contribution of the adaptive and maladaptive coping strategies accounted for an additional 13% of the variance in depression scores ($R = .70, F \text{ Change}(2, 115) = 14.34, p < .001$), which was significant, and the overall model remained significant, $F(10, 115) = 10.74, p < .001$. Maladaptive coping strategies was the only unique contributor (10%; $\beta = .40, t = 4.81, p < .001$) such that more maladaptive coping predicted higher depression. At Step 3, the combined contributions of the illness perception components, coping strategies and benefit finding accounted for 53% of the variance in depression and the full model was significant, $F(11, 114) = 11.46, p < .001$. After controlling for the contributions of the illness perception components and coping strategies, benefit finding accounted for an additional 4% in the variance in depression scores ($R = .73, F \text{ Change}(1, 114) = 10.10, p = .002$), such that greater benefit finding predicted higher depression scores ($\beta = .25, t = 3.18, p = .002$).

Predictors of Physical Health

There were a number of significant zero-order correlations among predictor variables and physical health ratings. Increased negative illness related consequence ($r = -.46$), illness identity ($r = -.47$), greater illness related concern ($r = -.33$), a greater negative emotional response to HCV ($r = -.42$), and higher adoption of more maladaptive coping strategies ($r = -.37$) were all associated with poorer physical health. Perceptions related to shorter illness duration ($r = -.28$) were associated with better physical functioning.

At Step 1, the combined illness perception components made a significant contribution to the model, $R = .58$, $R^2 = .33$, $F(8, 117) = 7.34$, $p < .001$. Higher illness identification was the only significant component to predict physical health scores (6%) such that greater illness identification predicted poorer physical health outcomes ($\beta = -.33$, $t = 3.37$, $p = .001$). At Step 2, the model was significant, $F(10, 115) = 7.76$, $p < .001$, accounting for 40% of the variance. Coping made a significant additional contribution to the prediction of physical health scores (7%) ($R = .64$, $R^2 \text{ Change} = .07$, $F \text{ Change}(2, 115) = 6.63$, $p = .002$). Maladaptive coping (7%) was the only significant contributor such that greater maladaptive coping predicted poorer physical health ($\beta = -.32$, $t = 3.63$, $p < .001$). At Step 3, the full model accounted for 40% of variance in physical health scores, and the model remained significant, $F(11, 114) = 7.02$, $p < .001$. Benefit finding however, failed to add to the model, $R = .64$, $R^2 \text{ Change} = .001$, $F \text{ Change}(1, 114) = .17$, $p = .682$.

Predicting Life Satisfaction

Greater personal control ($r = .50$), perceptions related to shorter illness duration ($r = -.20$), greater treatment control perceptions ($r = .16$), greater illness understanding or coherence ($r = .26$), greater adaptive ($r = .25$) and maladaptive (r

= .22) coping, and increased benefit finding ($r = .48$) were all significant zero-order correlates of greater life satisfaction. Greater illness concern ($r = -.23$) was associated with lower life satisfaction.

At Step 1, the illness perception components accounted for 33% of the variance in life satisfaction, $R = .57$, $F(8, 117) = 7.14$, $p < .001$. Perceptions related to a shorter illness duration or timeline (2% of variance; $\beta = -.18$, $t = 2.03$, $p = .045$) and greater personal control (16% of variance; $\beta = .44$, $t = 5.21$, $p < .001$) predicted greater life satisfaction. At Step 2, the overall model remained significant, $F(10, 115) = 7.84$, $p < .001$, with the combined contributions of the illness perception components and coping strategies accounting for 41% of the variance in life satisfaction. Coping strategies made a significant contribution to the model ($R = .64$, $R^2 \text{ Change} = .07$, $F \text{ Change}(2, 115) = 7.47$, $p = .001$). Maladaptive coping (3% of variance) was the only unique significant contributor; more maladaptive coping strategies predicted greater life satisfaction ($\beta = .22$, $t = 2.44$, $p = .016$). At Step 3, the full model was significant ($F(11, 114) = 8.84$, $p < .001$), and contributed 46% to the variance in life satisfaction scores. Benefit finding explained an additional 6% of the variance in life satisfaction, $R = .68$, $F \text{ Change}(1, 114) = 11.61$, $p = .001$; greater benefit finding was associated with greater life satisfaction, $\beta = .29$, $t = 3.41$, $p = .001$.

Predicting Positive Affect

There were a number of significant zero-order relationships between the predictors and positive affect. Increased personal ($r = .51$) and treatment control ($r = .18$) perceptions, greater illness understanding or coherence ($r = .21$), greater adoption of adaptive ($r = .38$) and maladaptive ($r = .33$) coping strategies, and increased benefit finding ($r = .58$) were associated with higher positive affect.

At Step 1, illness perceptions accounted for 27% of the variance in positive affect scores, $R = .52$, $F(8, 117) = 5.40$, $p < .001$. Greater perception of personal control (18%) was the only significant predictor of positive affect ($\beta = .47$, $t = 5.36$, $p < .001$). At Step 2, the model was significant, $F(10, 115) = 9.06$, $p < .001$, accounting for 44% of the variance in positive affect. Coping strategies contributed significantly to the prediction of positive affect, $R = .66$, $R^2 \text{ Change} = .17$, $F \text{ Change}(2, 115) = 17.59$, $p < .001$. Adaptive coping (4%; $\beta = .24$, $t = 2.93$, $p = .004$) and maladaptive coping (6%; $\beta = .30$, $t = 3.48$, $p = .001$) were both positively associated with positive affect. At Step 3, the full model was significant, $F(11, 114) = 12.69$, $p < .001$, and together the predictors accounted for 55% of the variance in positive affect. Benefit finding added a further 11% of explanatory power to the model, which was significant, $R = .74$, $F \text{ Change}(1, 114) = 27.84$, $p < .001$; greater benefit finding predicted greater positive affect ($\beta = .41$, $t = 5.28$, $p < .001$).

Table 6.4
Unstandardised Coefficients, Beta Weights and 95% Confidence Intervals for Hierarchical Regression Analyses for the Prediction of each Outcome Variable by the Predictor Variables ($N = 126$)

	Unstandardised Coefficients		Standardised Coefficient Beta	95% Confidence Intervals For B	
	B	Std. Error		Lower Bound	Upper Bound
Depression					
Step 1					
(Constant)	13.74	4.41		5.01	22.46
Illness consequences	.19	.47	.05	-.74	1.12
Illness timeline	.38	.36	.09	-.34	1.10
Personal control	-.67	.33	-.17*	-1.32	-.02
Treatment control	-.33	.45	-.06	-1.21	.56
Illness identity	1.06	.41	.25*	.25	1.86
Illness concern	-.45	.42	-.10	-1.29	.39
Illness coherence	-.83	.38	-.18*	-1.58	-.09
Emotional response	1.40	.43	.35**	.55	2.24
Step 2					
(Constant)	.08	4.92		-9.67	9.84
Adaptive coping	.01	.09	.01	-.16	.18
Maladaptive coping	.69	.14	.40**	.41	.98
Step 3					
(Constant)	-.89	4.75		-10.30	8.52

Benefit finding	.11	.03	.25**	.04	.18
<hr/>					
Physical health					
Step 1					
(Constant)	70.55	8.46		53.80	87.29
Illness consequences	-1.66	.90	-.21	-3.44	.12
Illness timeline	-.46	.70	-.06	-1.83	.92
Personal control	1.09	.63	.14	-.16	2.33
Treatment control	.10	.86	.01	-1.60	1.80
Illness identity	-2.62	.78	-.33**	-4.16	-1.08
Illness concern	.01	.81	.00	-1.60	1.62
Illness coherence	.98	.72	.11	-.45	2.40
Emotional response	-.73	.82	-.10	-2.36	.89
Step 2					
(Constant)	81.18	9.99		61.38	100.99
Adaptive coping	.32	.17	.15	-.03	.66
Maladaptive coping	-1.06	.29	-.32**	-1.64	-.48
Step 3					
(Constant)	81.45	10.06		61.53	101.37
Benefit finding	-.03	.07	-.04	-.17	.11
<hr/>					
Life satisfaction					
Step 1					
(Constant)	16.82	2.87		11.13	22.51
Illness consequences	.30	.31	.11	-.31	.90
Illness timeline	-.48	.24	-.18*	-.95	-.01
Personal control	1.12	.21	.44**	.69	1.53
Treatment control	-.10	.29	-.03	-.68	.48
Illness identity	.21	.26	.08	-.31	.73
Illness concern	-.51	.28	-.17	-1.06	.04
Illness coherence	.36	.25	.12	-.13	.84
Emotional response	-.20	.28	-.08	-.75	.36
Step 2					
(Constant)	9.14	3.38		2.46	15.83
Adaptive coping	.10	.06	.15	-.02	.22
Maladaptive coping	.24	.10	.22*	.05	.44
Step 3					
(Constant)	8.43	3.24		2.02	14.85
Benefit finding	.08	.02	.29**	.03	.13
<hr/>					
Positive affect					
Step 1					
(Constant)	10.31	1.76		6.83	13.79
Illness consequences	.03	.19	.02	-.34	.40
Illness timeline	-.01	.14	-.00	-.29	.28
Personal control	.70	.13	.47**	.44	.96
Treatment control	.06	.18	.03	-.30	.41
Illness identity	.12	.16	.07	-.20	.44
Illness concern	-.02	.17	-.01	-.35	.31
Illness coherence	.12	.15	.07	-.18	.42
Emotional response	-.14	.17	-.10	-.48	.20
Step 2					
(Constant)	3.59	1.92		-.22	7.40
Adaptive coping	.10	.03	.24**	.03	.16
Maladaptive coping	.20	.06	.30**	.08	.31
Step 3					
(Constant)	3.00	1.73		-.43	6.44
Benefit finding	.07	.01	.41**	.04	.09

* $p < .05$ ** $p < .01$

Mediation Analysis – Illness Perceptions, Coping, and Adjustment

A series of path analyses were conducted to determine the extent to which the relationships between each of the individual illness perception components and physical and psychosocial adjustment outcomes were mediated by adaptive or maladaptive coping strategies. Sixteen separate analyses were conducted and only results that identified mediation by coping are reported. The remaining tests were not significant.

First, the ability of maladaptive coping strategies to mediate the relationship between illness identity and depression was investigated. The results are shown in Figure 1. In separate standard regression tests, illness identity accounted for 14% of the variance in depression scores, $R = .39$, $F(1, 124) = 21.80$, $p < .001$, $\beta = .39$, and 4% of the variance in maladaptive coping, $R = .19$, $F(1, 124) = 4.79$, $p = .031$, $\beta = .19$. A hierarchical regression was conducted to determine whether maladaptive coping strategies would predict depression after controlling for illness identity. Illness identity was entered at Step 1 and maladaptive coping strategies were entered at Step 2. After controlling for illness identity, maladaptive coping strategies added a significant 22% of variance to the prediction of depression ($R = .61$, $F \text{ Change}(2, 123) = 42.31$, $p < .001$, $\beta = .48$). When maladaptive coping was entered at Step 2 of the model, the coefficient for illness identity decreased to $\beta = .30$, but continued to make a significant contribution to the model, $p < .001$. A Sobel test revealed that the decrease in the coefficient for illness identity was significant ($z = 2.075$, $p = .037$), indicating that maladaptive coping mediated the relationship between illness identity and depression.

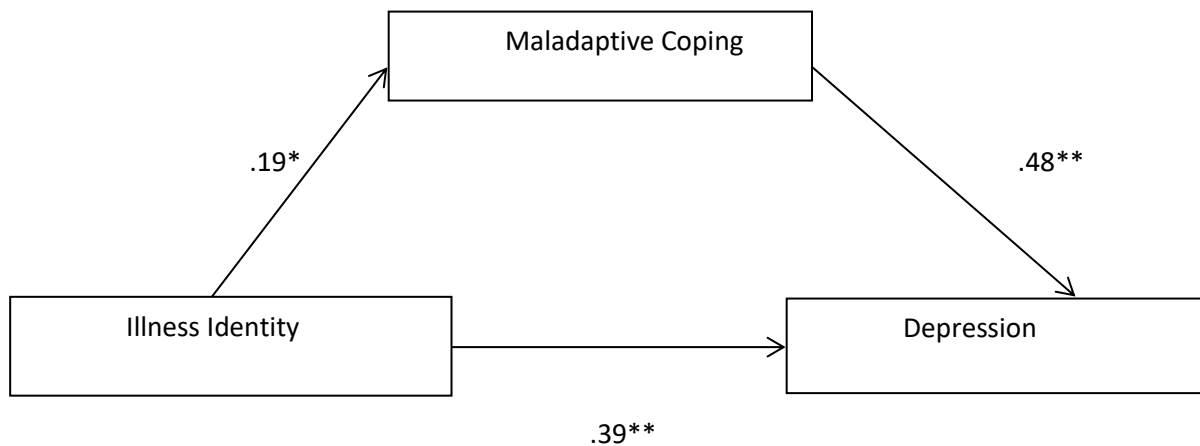


Figure 6.1

The direct and mediated pathways between illness identity and depression ** $p < .01$ * $p < .05$.

Second, standard and hierarchical regressions were conducted to assess whether maladaptive coping mediated the relationship between emotional response and depression (see Fig. 2). Following a standard regression, emotional response accounted for 22% of the variance in depression scores, $R = .47$, $F(1, 124) = 35.41$, $p < .001$, $\beta = .47$. In a subsequent standard regression, emotional response accounted for 14% of the variance in maladaptive coping, $R = .37$, $F(1, 124) = 20.10$, $p < .001$, $\beta = .37$. A hierarchical regression was used to assess the efficacy of maladaptive coping strategies to predict depression after controlling for emotional response. Emotional response was entered at Step 1 and maladaptive coping strategies were entered at Step 2. After accounting for the contributions of emotional response at Step 1, maladaptive coping strategies added a further 15% of the variance in depression which was significant ($R = .61$, $F \text{ Change}(2, 123) =$

28.80, $p < .001$, $\beta = .41$). When maladaptive coping was entered at Step 2, emotional response continued to make a significant contribution to the model ($p < .001$) following earlier independent standard regression analysis, but the coefficient decreased to $\beta = .32$. A Sobel test indicated that the decrease in the coefficient for emotional response was significant ($z = 3.436$, $p < .001$), confirming that maladaptive coping mediated the relationship between emotional response and depression.

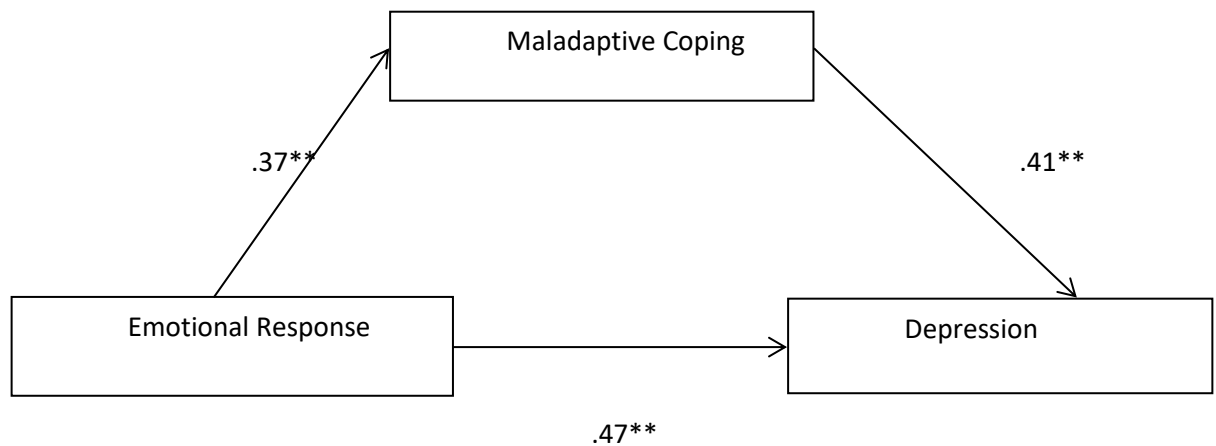


Figure 6.2

The direct and mediated pathways between emotional response and depression ** $p < .01$ * $p < .05$.

A third set of regressions assessed whether maladaptive coping mediated the relationship between illness identity and physical health (see Fig. 3). Identity accounted for 22% of the variance in physical health, $R = .47$, $F(1, 124) = 35.16$, $p < .001$, $\beta = -.47$, and 4% of the variance in maladaptive coping, $R = .19$, $F(1, 124) = 4.79$, $p = .031$, $\beta = .19$. A hierarchical regression was then utilised to determine the efficacy of maladaptive coping to account for variance in physical health

ratings after controlling for illness identity. Illness identity was entered at Step 1 and maladaptive coping strategies were entered at Step 2. Maladaptive coping added a significant 8% of the variance in physical health ratings after controlling for illness identity ($R = .55$, $F \text{ Change } (2, 123) = 14.42$, $p < .001$, $\beta = -.29$).

Although illness identity continued to make a significant contribution at Step 2 ($p < .001$) its contribution decreased ($\beta = -.41$). A Sobel test indicated that the decrease in the coefficient for illness identity at Step 1 of the model was marginally significant ($z = -1.896$, $p = .057$), indicating that maladaptive coping had partially mediated the relationship between illness identity and physical health.

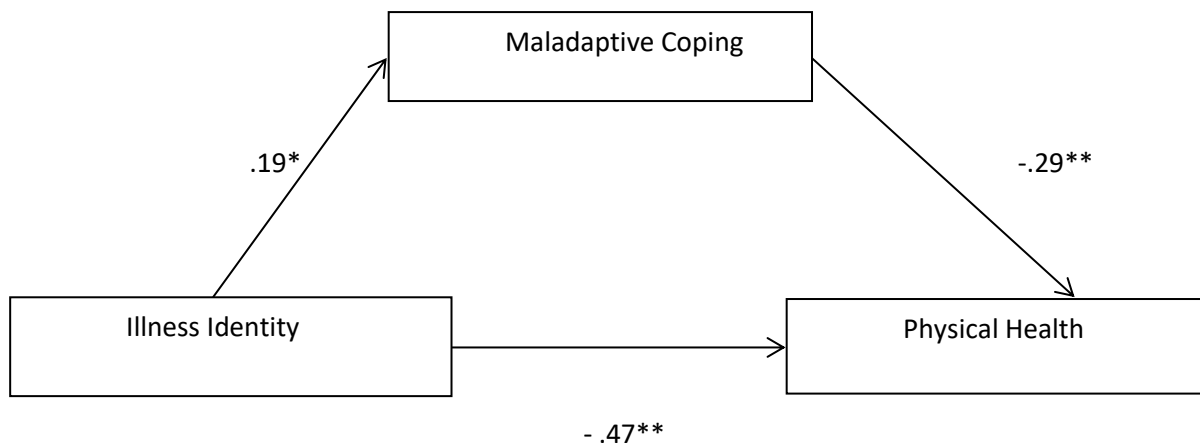


Figure 6.3 The direct and mediated pathways between illness identity and physical health ** $p < .01$ * $p < .05$.

Mediation Analysis – Illness Perceptions, Benefit Finding, and Adjustment

The relationships between individual illness perception components and physical and psychosocial adjustment outcomes were further investigated using path analyses to determine the extent to which the relationships between each of

the individual illness perception components and physical and psychosocial adjustment outcomes were mediated by benefit finding. In total eight separate analyses were conducted. Only results that identified mediation by benefit finding are reported.

First, standard and hierarchical regressions were conducted to assess whether benefit finding mediated the relationship between personal control and life satisfaction (see Fig. 4). Results of separate standard regressions indicated that personal control predicted 25% of the variance in life satisfaction scores, $R = .50$, $R^2 = .03$, $F(1, 124) = 41.44$, $p < .001$, $\beta = .50$, and 15% of the variance in benefit finding, $R = .38$, $F(1, 124) = 21.14$, $p < .001$, $\beta = .38$. A hierarchical regression was utilised to investigate whether benefit finding could account for variance in life satisfaction after first controlling for the contributions of personal control. Personal control was entered at Step 1 and benefit finding was entered at Step 2. Benefit finding contributed a significant 10% of the variance in life satisfaction results ($R = .59$, $F \text{ Change}(2, 123) = 17.78$, $p < .001$, $\beta = .33$). Personal control continued to make a significant contribution at Step 2 of the model ($p < .001$). However, the level of contribution decreased ($\beta = .37$). Sobel test results indicated that the decrease in the co-efficient for personal control was significant ($z = 3.074$, $p = .002$), indicating that benefit finding mediated the relationship between personal control and life satisfaction.

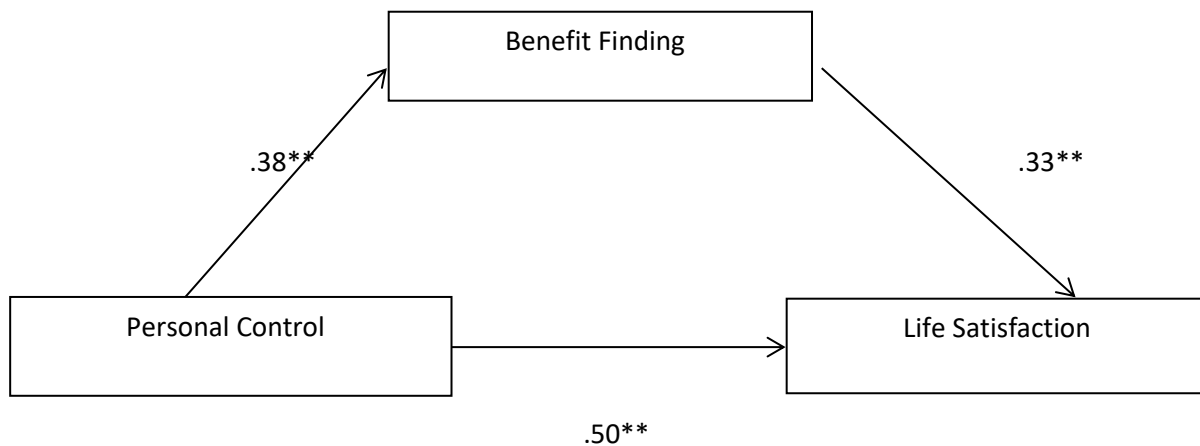


Figure 6.4

The direct and mediated pathways between personal control and life satisfaction

** $p < .01$ * $p < .05$.

Standard and hierarchical regressions were used to assess whether benefit finding mediated the relationship between personal control and positive affect (see Fig. 5). Results of separate standard regression tests indicated that personal control predicted 26% of the variance in positive affect scores, $R = .51$, $F(1, 124) = 43.05$, $p < .001$, $\beta = .51$ and 15% of the variance in benefit finding, $R = .38$, $F(1, 124) = 21.14$, $p < .001$, $\beta = .38$. A hierarchical regression investigated whether benefit finding predicted variance in positive affect after controlling for personal control. Personal control was entered at Step 1 and benefit finding was entered at Step 2. Benefit finding contributed an additional 18% of the variance in positive affect above that predicted by personal control ($R = .66$, $F \text{ Change}(2, 123) = 38.12$, $p < .001$, $\beta = .45$). Personal control continued to make a significant contribution at Step 2 of the model ($p < .001$). However, the level of contribution to the model decreased ($\beta = .34$). A Sobel test indicated that the decrease in the coefficient for

personal control was significant ($z = 3.666, p < .001$), indicating that benefit finding mediated the relationship between personal control and positive affect.

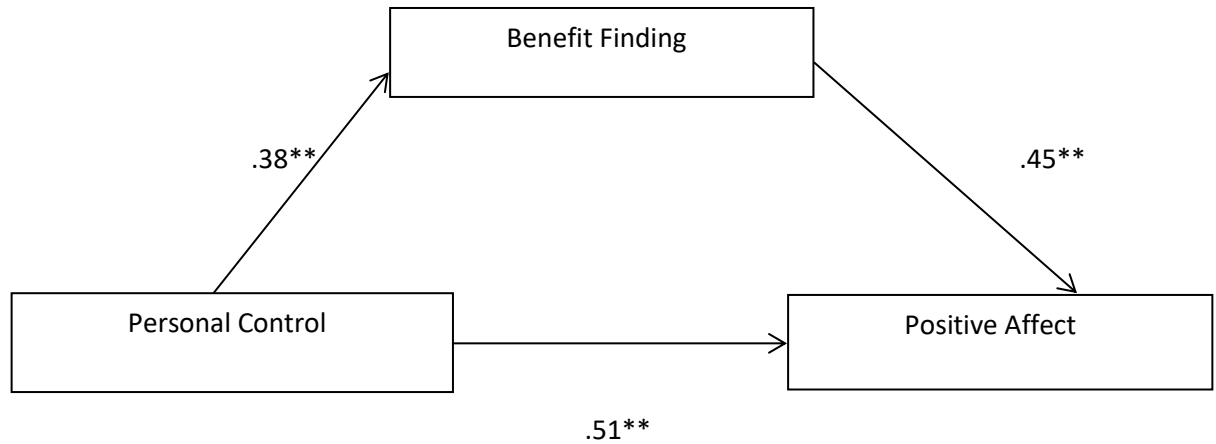


Figure 6.5

The direct and mediated pathways between personal control and positive affect ** $p < .01$ * $p < .05$.

6.3 Discussion

Study 1.1 explored relationships between illness perceptions, adaptive and maladaptive coping strategies, and benefit finding as predictors, and the illness adjustment outcomes of depression, physical health, life satisfaction, and positive affect as criterion variables within the context of HCV. Mediation tests were also conducted to identify the role of coping strategies and benefit finding to mediate relationships between illness perception components and criterion variables. First, consistent with related chronic disease studies, the combined illness perception components, and both adaptive and maladaptive coping strategies, made significant contributions in explainable variance across all four adjustment areas (Fortune et al., 2002; Helder et al., 2002; Rutter & Rutter, 2002; Scharloo et al., 2000). Benefit finding predicted depression, life satisfaction and positive affect adjustment

outcomes, but not physical health. These results are consistent with the contribution of benefit finding reported in related studies (Helgeson et al., 2006; Littlewood et al., 2008; Park et al., 2009; Tennen et al., 1992). Second, both coping strategies and benefit finding mediated the relationships between illness perceptions and physical and psychosocial adjustment. Further, to the finding that coping strategies mediated the relationships between illness perceptions and physical and psychosocial adjustment are consistent with results reported by Rutter and Rutter (2002).

Personal control, illness identity, illness coherence, and emotional response all made unique contributions to the variance in depression scores. These results are consistent with a number of related studies where illness perceptions accounted for significant variance in depression in other chronic diseases (Fortune et al., 2002; Helder et al., 2002; Rutter & Rutter, 2002; Scharloo et al., 2000; Vaughan et al., 2003). Specifically, a number of related studies identified illness identity as accounting for variance in depression across a number of chronic disease conditions including chronic fatigue syndrome (Heijmans 1998), rheumatoid arthritis, chronic obstructive pulmonary disease (Scharloo et al., 1998), psoriasis (Fortune et al., 2002), addisons disease (Heijmans, 1999), multiple sclerosis (Vaughan et al, 2003), breast cancer (Gibbons, Groarke, & Sweeney, 2016), and Huntington's disease (Helder et al., 2002). Taken together, the results reported for HCV and other chronic conditions identify common themes of higher illness symptom reporting predicting increased mood disturbance among individuals living with HCV and other chronic diseases.

Personal control made significant contributions to the variance in depression among individuals living with HCV. However, the role of personal

control in predicting depression has not been reported in a number of other related chronic disease studies (Heijmans, 1998; Heijmans, 1999; Scharloo et al., 1998; Helder et al., 2002). It should be noted that these studies used a combined control/cure variable, included in earlier versions of illness perception questionnaires, reflecting how much personal control an individual believes they have over their illness, and how much they believe treatment can assist with managing their illness measured in a single variable. This may have contributed to the discrepancies reported between the role of personal control in predicting depression among individuals with HCV in comparison to these other chronic conditions.

In the present study higher levels of illness coherence or understanding predicted lower depression, whereas greater negative emotional responses to HCV predicted higher depression. These results are consistent with a study conducted among individuals diagnosed with type 2 diabetes (Joshi, Dhungana, & Subba, 2015). In this study, a higher emotional response to diabetes predicted greater depression, whilst a greater illness understanding or coherence predicted lower depression (Joshi et al., 2015). Similar to personal control, illness coherence and emotional response were not included in early illness perception questionnaires. This may have contributed to possible under reporting of the potential for these variables to make significant contributions to prediction of depression in related chronic disease conditions, in comparison to illness identity which has been included in earlier and more recent versions of illness perception measures (Moss-Morris et al., 2002).

Chronic illness has been associated with more negative consequences for individuals living with longer term health conditions (Broadbent et al., 2015).

Often chronic conditions have the potential to negatively impact a range of areas in an individual's daily life. This has been reflected in a number of studies that have investigated the role of illness consequence in predicting depression among individuals impacted by longer term illness (Fortune et al., 2002; Heijmans, 1999; Rutter & Rutter, 2002; Vaughan et al., 2003). Interestingly, in contrast to these related chronic disease studies that have consistently found significant positive associations between illness consequence and depression (Fortune et al., 2002; Heijmans, 1999; Rutter & Rutter, 2002; Vaughan et al., 2003), illness consequence did not predict depression among individuals living with HCV. This finding suggests that the impact of living with HCV as reported here was not associated with lower mood, in comparison to individuals living with other related chronic disease conditions such as multiple sclerosis where the reporting of higher levels of negative consequence is more consistently reported (Vaughan et al., 2003). In contrast, a reasonably high degree of variance in the reporting of illness related symptoms associated with the experience of living with HCV as reported in the literature may have contributed to this finding (Forton et al., 2003; Lee & Abdo, 2003; Lee & Harrison, 2005).

Illness identity was the only illness perception component to make a unique contribution to the prediction of physical health outcomes. A number of related studies have found similar associations between increased identification with illness symptoms and decreased physical health (Heijmans, 1998; Heijmans, 1999; Helder et al., 2002; Scharloo et al., 2000). For example, Scharloo et al. (2000) reported strong negative associations between illness identity and physical health among individuals with psoriasis. However, Vaughan et al. (2003) did not identify a significant predictive relationship between illness identity and physical health

among a group of individuals diagnosed with multiple sclerosis. Other studies demonstrated significant predictive links between illness consequence and physical health, not found in the present analysis among individuals living with HCV (Fortune et al., 2002; Heijmans, 1998; Heijmans, 1999; Rutter & Rutter, 2002; Vaughan et al., 2003). It may be that among individuals living with HCV, the identification and reporting of symptoms associated with their condition is more strongly associated with reported depression and physical functioning in comparison to a number of related chronic conditions where both illness identity and illness consequence have accounted for variance in physical health and depression outcomes (Broadbent et al., 2015; Hagger & Orbell, 2003; Heijmans, 1998; Heijmans, 1999).

Personal control made unique and significant contributions to both life satisfaction and positive affect. These significant individual contributions highlight the important associations between how much an individual believes their actions can control their illness and perceived quality of life, and are consistent with a number of related chronic disease studies (Rutter & Rutter, 2002; Vaughan et al., 2003). Further, shorter illness duration predicted increased life satisfaction independent of coping and benefit finding. These data are inconsistent with a number of related chronic disease studies that failed to demonstrate a link between illness timeline and psychological well-being (Fortune et al., 2002; Rutter & Rutter, 2002; Vaughan et al., 2003), and may be related to the unique potential for a treatment cure that potentially exists for HCV that sets this disease apart from other chronic health conditions where the focus is generally more on longer term management (e.g., multiple sclerosis).

After controlling for illness perceptions, maladaptive coping and adaptive coping were less reliable predictors of HCV physical and psychosocial adjustment outcomes when compared to the relative contributions of illness perception components. However, similar to a number of related chronic disease studies, increased adoption of maladaptive coping strategies was associated with higher depression (Helder et al., 2002; Rogan et al., 2013; Rutter & Rutter, 2002; Scharloo et al., 2000). Collectively, the greater adoption of illness related denial, substance use, use of emotional venting, self-blame, and behavioural disengagement coping strategies predicted higher depression. Similarly, Helder et al. (2002) found significant links between the adoption of emotional venting coping strategies and depression, and Rutter and Rutter identified greater behavioural disengagement strategies as contributing to higher depression in other chronic disease conditions. Together, these data suggest that individuals who adopt maladaptive coping strategies in response to their chronic illness, including HCV, are more likely to experience higher levels of mood disturbance. Further, greater adoption of maladaptive coping strategies was associated with poorer physical health outcomes. These data are consistent with Helder et al. (2002) who demonstrated the role of increased behavioural disengagement in contributing to reduced physical health among a cohort of individuals with psoriasis. Interestingly, at a more adaptive level, active coping strategies accounted for variance in health related outcomes among individuals with irritable bowel syndrome (Rutter & Rutter, 2002). A number of factors may have contributed to the variability across chronic disease studies in reporting links between maladaptive coping strategies and depression and physical health adjustment relevant to the present study. For example, a number of chronic disease studies have not included the measurement

of coping, focussing instead on the contributions of illness perceptions to the prediction of physical and psychosocial adjustment (Hagger & Orbell, 2003). Further, studies that have included coping strategies have used a variety of standardised coping measures (Broadbent et al., 2015; Hagger & Orbell, 2003). Collectively, these factors may have limited the ability to compare the relative contributions of coping strategies reported for HCV in comparison to other chronic health conditions, and may have contributed to the under-reporting of the role of coping in predicting adjustment within the context of chronic disease.

Increased adoption of maladaptive coping strategies predicted higher life satisfaction and positive affect. This finding has not been reported in other chronic disease studies which have more identified inverse relationships between maladaptive coping strategies and quality of life outcomes (Heijmans, 1998; Helder et al., 2002; Rutter & Rutter, 2002). For example, Helder et al. (2002) identified associations between lower avoidance, less emotional and improved quality of life among individuals living with chronic fatigue syndrome. These results may indicate the potential for both adaptive and maladaptive coping strategies within the context of HCV to contribute to improved quality of life, reflecting the variance in individual perceptions and coping behaviours that can exist across the spectrum of chronic disease. Perhaps for some individuals living with the experience of HCV, adopting more maladaptive coping strategies associated with denial or substance use may help to suppress unpleasant feelings and emotions associated with their HCV, leading to improved life satisfaction. Further, consistent with other chronic disease studies, adaptive coping strategies were positively and uniquely associated with positive affect (Rutter & Rutter, 2002). Specifically, Rutter and Rutter (2002) identified an important role for

increased illness related acceptance in predicting better quality of life among individuals living with irritable bowel syndrome.

Results concerning the efficacy of benefit finding to account for variance across HCV physical and psychosocial adjustment were in line with a number of related studies, however, inconsistent findings have also been reported (Helgeson et al., 2006; McMillen & Fisher, 1998; Sears et al., 2003; Tomich & Helgeson, 2004). For example, in the present study, greater benefit finding predicted higher depression after controlling for illness perceptions and coping. Similarly, McMillen and Fisher (1998) identified links between three benefit finding features; increased compassion, greater positive lifestyle changes, increased family closeness, and higher depression among individuals who had experienced an adverse life event, that included chronic illness. In accounting for these relatively counter-intuitive findings, McMillen and Fisher suggested that benefit finding and depression could theoretically and practically occur simultaneously, such that individuals may potentially discover benefits from their experience of chronic disease whilst continuing to experience decreased mood (McMillen & Fisher, 1998).

Consistent with results reported by Helgeson et al. (2006), benefit finding failed to predict physical health outcomes after controlling for the combined contributions of both illness perceptions and coping strategies. However, in a related study, Luszczynska et al. (2007) found that increased benefit finding predicted increased physical functioning among a group of women and men diagnosed with the human immunodeficiency virus. It may be that issues related to differences in study methodology contributed to the discrepancy in findings reported across these studies. For example, findings reported in Helgeson et al.

(2006) were drawn from 87 cross-sectional studies following a meta-analysis design that investigated relations between benefit finding and psychosocial and physical adjustment among individuals who had experienced adverse life events, including chronic disease. In contrast, results published by Luszczynska et al. (2007) followed a single cross-sectional study ($n = 104$) measuring benefit finding among individuals diagnosed with human immunodeficiency virus.

Greater benefit finding predicted both increased positive affect and greater life satisfaction. These results are consistent with other work that identified important associations between benefit finding and positive wellbeing (Helgeson et al., 2006; Park et al., 2009; Tennen et al., 1992). For example, Tennen et al. identified the efficacy of benefit finding to predict positive well-being among a cohort of individuals with rheumatoid arthritis. However, other chronic disease studies failed to demonstrate these predictive relationships. For example, Tomich and Helgeson (2004) reported that benefit finding did not predict positive affect outcomes (in a sample of breast cancer sufferers).

Consistent with Rutter and Rutter (2002), coping strategies mediated some, but not all of the relationships between illness perceptions and physical and psychosocial adjustment. In the present study, illness identity and maladaptive coping strategies were strong predictors of depression. Results also indicated that maladaptive coping strategies mediated the relationship between illness identity and depression. Individuals reporting more symptoms associated with their HCV were more likely to engage in maladaptive coping strategies and report greater depressive symptomology. Similarly, the relationship between emotional response perceptions and depression was mediated by maladaptive coping. Greater emotional response to HCV and maladaptive coping strategies predicted significant

variance in depression scores, and individuals reporting greater negative emotional responses to their HCV were more likely to engage with maladaptive coping strategies. Further, maladaptive coping partially mediated the relationship between illness identity and physical health outcomes. Higher reporting of identification with HCV symptoms and greater adoption of maladaptive coping strategies partially predicted poorer physical health, and individuals reporting more HCV symptoms were more likely to engage in maladaptive coping strategies.

A few related chronic disease studies have assessed whether coping strategies mediated the relationship between illness perceptions and physical and psychosocial adjustment (Hagger & Orbell, 2003; Rutter & Rutter, 2002). For example, Rutter and Rutter (2002) reported that among individuals diagnosed with irritable bowel syndrome; (1) acceptance mediated the relationship between illness consequence and psychosocial adjustment. Individuals reporting lower negative consequences associated with their illness were more likely to accept their condition and reported improved quality of life, (2) active coping mediated the relationship between cure/control perceptions and physical health adjustment. Individuals who reported higher illness related personal and treatment control beliefs were more likely to engage in active coping strategies and report greater satisfaction regarding their health, and (3) behavioural disengagement mediated the relationship between cure/control perceptions, whilst negative venting of emotions mediated the relationship between psychological causation beliefs, illness consequence and anxiety. These differences in mediation mechanisms between HCV and irritable bowel syndrome highlight how differences in disease processes can contribute to differences in the manifestation of illness perceptions and coping strategies which can in turn contribute to variance in health related outcomes. They

also highlight how variations in both illness perception and coping measures used across chronic disease studies can account for differences in adjustment outcomes. For example, emotional response was measured in the present study but not in Rutter and Rutter. Despite these differences, results reported for HCV identify the potential for psychological interventions that specifically assist individuals to improve their ability to self-regulate symptoms associated with their HCV, and refrain from adopting maladaptive coping strategies, may contribute to improved mood and physical health. Similarly, addressing perceptions related to emotional response and providing interventions that decrease the adoption of maladaptive coping strategies, may also contribute less depression.

No published research to date has assessed whether benefit finding mediated the relationships between illness perceptions and physical and psychosocial adjustment outcomes within the context of HCV. In the present study, benefit finding mediated the relationships of personal control to life satisfaction and positive affect. In both models, personal control and benefit finding predicted significant variance in life satisfaction and positive affect. Mediation test results suggested that individuals with stronger perceptions related to illness related personal control were likely to engage with higher levels of benefit finding contributing to improved quality of life in relation to their HCV. In comparison, a relatively small number of studies have assessed whether benefit finding mediated the relationship between illness perceptions and adjustment outcomes in related chronic diseases (Helgeson et al., 2006; Luszczynska et al., 2007). In one study, Luszczynska et al. investigated links between self-efficacy (a closely related construct of personal control), benefit finding, medication adherence and physical health among a cohort of individuals living with the human

immunodeficiency virus. Results suggested that benefit finding mediated the relationship between self-efficacy, medication adherence and physical adjustment. Individuals who reported greater illness specific self-efficacy were more likely to discover positive benefits and meaning in relationship to their illness and report increased medication adherence and improved physical health (Luszczynska et al., 2007). The results reported in the present study and in Luszczynska et al. (2007) identify common links between greater self-efficacy/personal control perceptions, higher benefit finding and improved health outcomes for individuals living with both HCV and the human immunodeficiency virus.

The results reported in Study 1.1 support the role of illness perceptions and coping strategies in predicting physical and psychosocial adjustment among individuals with HCV (Fortune et al., 2002; Helder et al., 2002; Rutter & Rutter, 2002; Scharloo et al., 2000). The results reported here also demonstrate the efficacy of benefit finding to predict psychosocial adjustment outcomes in individuals with HCV. Further, these results identified the efficacy of coping strategies and benefit finding to mediate relationships between illness perception components and physical and psychosocial adjustment outcomes. Finally, in clinical practice, previous research has demonstrated the effectiveness of psychological interventions in improving illness related adjustment among individuals with chronic illness (Daleboudt et al., 2013; Goodman, Morrissey, Graham, & Bossingham, 2005). Results reported here support the potential application of psychological interventions that focus on modifying illness perceptions, increasing adaptive coping strategies, and assisting individuals to identify illness related benefits, with the aim of increasing physical and psychosocial adjustment among individuals with HCV.

6.4 General comments

The limitations relevant to the present study are reported in greater detail in Chapter 8. Results reported here have demonstrated that illness perceptions and coping strategies (as proposed by the SRM) along with benefit finding are important predictors of physical and psychosocial adjustment outcomes in HCV. In some, but not all cases, coping mediated relationships between illness perceptions and physical and psychosocial adjustment. Further, benefit finding mediated some of the relationships between illness perception components and adjustment.

In related chronic disease research (Hagger & Orbell, 2003; Vaughan et al., 2003) there has been significant debate as to the relative importance of coping strategies to the prediction of adjustment outcomes among individuals with chronic disease. Study 1.2 assesses whether coping strategies can independently predict physical and psychosocial adjustment among individuals with HCV, along with assessing the predictive ability of illness perceptions when the traditional SRM order of entry into predictive models is reversed (Leventhal et al., 1980).

Study 1.2 - The Role of Coping in Adjustment Outcomes in Hepatitis C

Introduction 6.5

As reported in Study 1.1, illness perceptions and coping strategies made significant contributions to predicting variance in physical and psychosocial adjustment. Further, following the traditional order of entry into the SRM as outlined by Leventhal et al. (1980), maladaptive coping strategies mediated the relationships of illness identity and emotional response to depression, but only partially mediated the relationship between illness identity and physical health. These results are consistent with a growing body of research that has confirmed the efficacy of illness perceptions to predict physical and psychosocial adjustment outcomes across a range of chronic diseases (Daleboudt et al., 2013; De Gucht, 2015; Fortune et al., 2002; Greco et al., 2014).

The results reported in Study 1.1 indicated that coping strategies were a significant predictor of physical and psychosocial adjustment in HCV. These results were in contrast to numerous studies that have investigated the efficacy of the coping strategies to predict variance in adjustment across the spectrum of chronic disease, which have not consistently found such relationships (Hagger & Orbell, 2003; Helder et al., 2002; Heijmans, 1999; Steed et al., 1999). Overall, there are more reports implicating illness perceptions than coping strategies as key variables in accounting for variance in adjustment outcomes across the spectrum of chronic disease (Broadbent et al., 2015; Hagger & Orbell, 2003).

The majority of studies of chronic disease that have investigated the efficacy of the SRM to predict adjustment have followed the traditional order of entry, as outlined by Leventhal et al. (1992), which typically involves illness perception components being entered into the regression models at Step 1, and

coping strategies entered at Step 2 (Fortune et al., 2002; Rutter & Rutter, 2002; Steed et al., 1999). Other studies either performed separate tests for the illness perceptions and coping strategies (Helder et al., 2002), or varied the order of entry of SRM features into separate regression models (Heijmans, 1999). Further, a number of studies have not included coping strategies within SRM predictive frameworks due to data suggesting that illness perceptions are better predictors of physical and psychosocial adjustment (Heijmans, 1998; Moss-Morris et al., 1996; Vaughan et al., 2003). Results reported in Study 1.1 however, indicated a significant role for maladaptive coping in predicting physical and psychosocial adjustment outcomes across all four criterion variables in HCV. In comparison, adaptive coping strategies only contributed to the variance in the positive affect adjustment outcome. In light of these reported inconsistencies both across existing chronic disease literature (Hagger & Orbell, 2003), and in Study 1.1, the primary aim of Study 1.2 was to assess whether coping strategies independently predicted physical and psychosocial adjustment outcomes among individuals diagnosed with HCV.

Following an approach similar to the one used by Heijmans (1999), for each of the regression tests a non-traditional approach was adopted and the order of entry into the regression models was reversed (Leventhal et al., 1980). Therefore, for each of the regression tests, coping strategies were entered at Step 1 and illness perceptions at Step 2. Entering coping strategies at Step 1 provided an opportunity to assess whether both adaptive and maladaptive coping independently predicted physical and psychosocial adjustment, and whether the components of illness perception predicted adjustment outcomes after first controlling for coping.

Study 1.2 employed the same indices of depression (Fortune et al., 2002; Vaughan et al., 2003), life satisfaction, positive affect (De Gucht, 2015; Rutter & Rutter, 2002) as measures of psychosocial adjustment, and physical health as a measure of physical adjustment (Heijmans, 1999; Steed et al., 1999) as used in Study 1.1. Hypotheses were (1) Adaptive and maladaptive coping strategies would make significant contributions to the adjustment models independent of illness perception components. (2) After entry at Step 2 of the predictive models, illness perception components would make significant contributions to the four criterion variables.

6.6 Method

The same participants, measures, and procedure used in Study 1.1 were employed in Study 1.2

6.6.1 Data Analysis

Hierarchical regression analyses were conducted to confirm the relative contributions of illness perceptions and coping strategies in predicting physical and psychosocial adjustment outcomes. Separate analysis was conducted for each of the criterion variables (depression, physical health, life satisfaction, and positive affect). For each test coping strategies were entered at Step 1, and illness perception components were entered at Step 2.

6.6.2 Results

Model for Predicting Depression

Hierarchical regression analysis was conducted to assess (1) the contribution of coping strategies to variance in depression independent of the illness perception components, and (2) the efficacy of illness perceptions to predict depression after first controlling for the contributions of coping strategies. The

unstandardised coefficients, beta weights, and confidence intervals for all variables and tests are summarised in panel 1 of Table 6.5. At Step 1, the model was significant, $F(2,123) = 24.53, p < .001$, with coping strategies accounting for 29% of the variance in depression scores, $R = .53, F(2, 123) = 24.53, p < .001$. Only maladaptive coping made a significant contribution to the prediction of depression accounting for 26% of the variance in depression scores, which was significant, $\beta = .55, t = 6.67, p < .001$. Greater adoption of maladaptive coping predicted greater depression. At Step 2, the full model was significant, $F(10,115) = 10.74, p < .001$, and the combined contributions of the illness perception components and coping strategies accounted for 48% of the variance in depression scores. At Step 2, the illness perception components accounted for an additional 20% of variance in depression, which was significant, $R = .70, F \text{ Change } (8, 115) = 5.50, p < .001$. Only personal control (4%), $\beta = -.21, t = 2.80, p = .006$, and illness identity (3%), $\beta = .24, t = 2.77, p = .007$, made unique and significant contributions to prediction of depression.

Model for Predicting Physical Health.

To determine whether a non-traditional SRM was able to predict physical health, coping strategies were entered at Step 1 and illness perception components at Step 2. The unstandardised coefficients, beta weights, and confidence intervals for all variables and tests are summarised in panel 2 of Table 6.5.

As can be seen in the table, the model was significant at Step 1, $R = .40, R^2 = .16, F(2,123) = 11.65, p < .001$, and together coping strategies accounted for 16% of the variance in physical health. Maladaptive coping was the only significant unique predictor (16%), $\beta = -.43, t = 4.83, p < .001$; more maladaptive coping predicted poorer physical health. At Step 2, the combined contributions of

the illness perception components and coping strategies accounted for 40% of the variance in physical health scores, and the full model was significant, $F(10,115) = 7.76, p < .001$. The addition of the illness perception components made a significant contribution to predicting physical health, adding an additional 24% to the model, $R = .63, F \text{ Change}(8, 115) = 5.87, p < .001$. Illness identity made a significant unique contribution to the prediction of physical health adjustment (6%), $\beta = -.31, t = 3.41, p = .001$; those who reported greater illness identity tended to report poorer physical health. Further, personal control predicted physical health (2%), $\beta = .17, t = 2.15, p = .034$; greater perceptions related to personal control predicted better physical health.

Model for Predicting Life Satisfaction.

A third hierarchical regression was performed on life satisfaction. Coping strategies were entered at Step 1 and illness perception components at Step 2. The unstandardised coefficients, beta weights, and confidence intervals for all variables and tests are summarised in panel 3 of Table 6.5. At Step 1 the model was significant, $R = .28, R^2 = .08, F(2,123) = 5.40, p = .006$, and together coping strategies collectively accounted for 8% of variance in life satisfaction. At an individual level, only greater adoption of adaptive coping strategies (3%) predicted increased life satisfaction, $\beta = .20, t = 2.10, p = .038$. At Step 2, the combined contributions of the illness perception components and coping strategies predicted 41% of the variance in life satisfaction which was significant, $R = .64, F(10,115) = 7.84, p < .001$. At Step 2, the illness perception components made a significant contribution to predicting life satisfaction, adding an additional 33% of explained variance to the model, $R = .64, F \text{ Change}(8, 115) = 7.85, p < .001$. Personal

control (14%), $\beta = .41$, $t = 5.14$, $p < .001$, and illness timeline (3%), $\beta = -.21$, $t = 2.48$, $p = .015$, were the only significant unique predictors of life satisfaction.

Model for Predicting Positive Affect.

A fourth test assessed whether coping strategies entered at Step 1, and illness perception components entered at Step 2, could predict positive affect. The unstandardised coefficients, beta weights, and confidence intervals for all variables and tests are summarised in panel 4 of Table 6.5. At Step 1 the model was significant, $R = .43$, $R^2 = .19$, $F(2,123) = 13.99$, $p < .001$, and together coping strategies collectively accounted for 19% of variance in positive affect. Greater adoption of both adaptive (8%), $\beta = .30$, $t = 3.46$, $p < .001$, and maladaptive coping strategies (4%), $\beta = .21$, $t = 2.39$, $p = .018$, predicted positive affect. At Step 2, the combined contributions of the coping strategies and illness perception components predicted 44% of the variance in positive affect which was significant, $R = .66$, $F(10,115) = 7.84$, $p < .001$. At Step 2, the illness perception components made a significant contribution accounting for an additional 26% the variance in positive affect, $R = .66$, $F \text{ Change } (8, 115) = 6.56$, $p < .001$. Personal control (15%), $\beta = .43$, $t = 5.55$, $p < .001$, and emotional response (3%), $\beta = -.27$, $t = 2.47$, $p = .015$, were the only significant unique predictors of positive affect.

Table 6.5
Unstandardised Coefficients, Beta Weights and 95% Confidence Intervals for
Multiple Regression Analyses for the Prediction of each Outcome Variable by the
Coping Strategies and Illness Perception Components ($N = 126$)

	Unstandardised Coefficients		Standardised Coefficient	95% Confidence Intervals For B	
	B	Std. Error	Beta	Lower Bound	Upper Bound
Depression					
Step 1					
(Constant)	-.33	4.16		-8.56	7.91
Adaptive coping	-.05	.09	-.05	-.23	.13
Maladaptive coping	.95	.14	.55*	.67	1.24
Step 2					
(Constant)	.08	4.92		-9.67	9.84
Illness consequences	.10	.43	.03	-.74	.95
Illness timeline	.31	.33	.08	-.34	.97
Personal control	-.83	.30	-.21*	-1.42	-.24
Treatment control	-.29	.41	-.05	-1.10	.53
Illness identity	1.01	.37	.24*	.29	1.74
Illness concern	-.06	.39	-.01	-.83	.71
Illness coherence	-.50	.36	-.11	-1.21	.21
Emotional response	.70	.41	.18	-.11	1.51
Physical Health					
Step 1					
(Constant)	65.82	8.53		48.93	82.70
Adaptive coping	.32	.18	.16	-.04	.69
Maladaptive coping	-1.42	.29	-.43*	-1.10	-.84
Step 2					
(Constant)	81.19	9.10		61.38	100.99
Illness consequences	-1.41	.86	-.18	-3.12	.30
Illness timeline	-.56	.67	-.07	-1.89	.77
Personal control	1.30	.60	.17*	.10	2.50
Treatment control	-.25	.84	-.02	-1.90	1.41
Illness identity	-2.53	.74	-.31*	-4.00	-1.06
Illness concern	-.56	.79	-.06	-2.13	1.01
Illness coherence	.19	.73	.02	-1.26	1.64
Emotional response	.12	.83	.01	-1.52	1.76
Life Satisfaction					
Step 1					
(Constant)	9.96	3.02		3.99	15.94
Adaptive coping	.14	.07	.20*	.01	.26
Maladaptive coping	.16	.10	.14	-.05	.37
Step 2					
(Constant)	9.14	3.38		2.46	15.83
Illness consequences	.30	.29	.11	-.28	.88
Illness timeline	-.56	.23	-.21*	-1.01	-.11
Personal control	1.05	.20	.41*	.64	1.45
Treatment control	-.17	.28	-.05	-.73	.39
Illness identity	.20	.25	.07	-.30	.70
Illness concern	-.37	.28	-.12	-.89	.16
Illness coherence	.39	.25	.13	-.09	.88
Emotional response	-.50	.28	-.20	-1.05	.06
Positive Affect					
Step 1					
(Constant)	6.41	1.67		3.11	9.71

Adaptive coping	.12	.04	.30*	.05	.19
Maladaptive coping	.14	.06	.21*	.02	.25
Step 2					
(Constant)	3.59	1.92		-.22	7.40
Illness consequences	.04	.17	.02	-.29	.37
Illness timeline	-.08	.13	-.05	-.34	.17
Personal control	.65	.12	.43*	.42	.88
Treatment control	-.01	.16	-.01	-.33	.30
Illness identity	.11	.14	.07	-.17	.39
Illness concern	.10	.15	.06	-.20	.40
Illness coherence	.14	.14	.08	-.14	.41
Emotional response	-.39	.16	-.27*	-.71	-.08

* $p < .05$

6.7 Discussion

Study 1.2 assessed whether coping strategies predicted physical and psychosocial adjustment outcomes independently of illness perceptions. Consistent with the results reported in Study 1.1, and with previous chronic disease related research (Fortune et al., 2002; Helder et al., 2002; Rutter & Rutter, 2002; Scharloo et al., 2000), and as hypothesised, both coping strategies and illness perceptions made significant contributions to adjustment.

The coping strategies data in the present study were in line with a number of related chronic disease studies (Fortune et al., 2002; Heijmans, 1999; Helder et al., 2002; Rutter & Rutter, 2002) that reported a relationship between maladaptive coping and depression. For example, both Fortune et al. (2002) and Heijmans (1999) reported that avoidant coping strategies predicted higher depression among individuals diagnosed with chronic disease. Further, Rutter and Rutter (2002) reported that engagement of coping strategies related to behavioural disengagement and suppression in response to chronic disease predicted higher depression among individuals with irritable bowel syndrome. Together, these data

suggest greater adoption of maladaptive coping strategies predicts higher depression, irrespective of chronic disease type.

As reported in Study 1.1, and consistent with related research (Fortune et al., 2002; Helder et al., 2002; Rutter & Rutter, 2002; Scharloo et al., 2000; Vaughan et al., 2003), illness perceptions related to personal control, illness identity, illness coherence, and emotional response to HCV each made significant and unique contributions to predicting depression. In the present study, after controlling for the contribution of coping strategies, only personal control and illness identity continued to make significant unique contributions to the model. These data highlight the relative robustness of these illness perception variables in adjustment for individuals with HCV.

Maladaptive coping strategies predicted poorer physical health, decreased physical and role functioning, increased physical pain and more negative perceptions of general health both independently, and after controlling for the contributions of illness perceptions. Consistent with these results, Fortune et al. (2002) identified the unique role of avoidance related to behavioural disengagement in contributing to variance in physical functioning. Similarly, Helder et al. (2002) described the role of behavioural disengagement in accounting for variance in physical health.

Illness identity accounted for significant variance in physical health independent of (reported in Study 1.1), and after controlling for, the contribution of coping strategies. Similar to related research (Heijmans, 1999; Helder et al., 2002; Scharloo et al., 2000), greater identification with the symptoms related to HCV was associated with poorer physical health. After controlling for coping strategies, personal control emerged as a significant predictor of physical health. These data

are in line with Rutter and Rutter (2002) who identified the role of increased illness related personal control in predicting higher satisfaction with health among a group of individuals with irritable bowel syndrome. Taken together, the results reported here highlight the relative importance of the relations between illness identity, personal control and physical health adjustment in comparison to that of other illness perception components, and support interventions for individuals that present with HCV that seek to increase a greater sense of illness related self-efficacy or personal control, along with interventions that promote more adaptive symptom management strategies with the aim of improving physical health adjustment.

The data reported in Study 1.2 are consistent with Rutter and Rutter (2002), who indicated that stronger adoption of adaptive coping strategies predicted increased life satisfaction independent of the illness perception components. This result was in contrast to results reported in Study 1.1, where after controlling for the contributions of illness perceptions only maladaptive coping strategies contributed to the model. As reported in Study 1.1, these results indicate that the adoption of both adaptive and maladaptive coping strategies can simultaneously contribute to improved life satisfaction which may be relatively unique to HCV.

Similar to results reported in Rutter and Rutter (2002), in the present study, personal control accounted for significant variance in life satisfaction results after controlling for the contribution of coping strategies. These results demonstrate the predictive link between higher perceptions of illness related personal control and higher perceptions of life satisfaction, and have important implications for clinical practice. The data reported in Studies 1.1 and 1.2 that identified perceptions related to a shorter illness timeline predicting higher life satisfaction, regardless of order of

entry into predictive models, reflect the relatively unique potential for a treatment cure for individuals presenting with HCV in comparison to most other chronic disease conditions (Hagger & Orbell, 2003).

As reported in Studies 1.1 and 1.2, maladaptive and adaptive coping strategies made significant contributions to the prediction of positive affect regardless of their order of entry into predictive models. Taken together with the results reported in Studies 1.1 and 1.2 in relation to the predictive links between adaptive and maladaptive coping strategies and life satisfaction, these results highlight the relatively unique potential in HCV for greater adoption of both adaptive and maladaptive coping strategies to contribute to improved quality of life.

As reported in Studies 1.1 and 1.2, personal control predicted positive affect independently and after controlling for the contributions of coping strategies. The results reported here for personal control are consistent with a number of other chronic disease studies that identified links between greater personal control perceptions and improved quality of life (Rutter & Rutter, 2002; Vaughan et al., 2003). Interestingly, lower negative emotional response to HCV emerged as a predictor of increased positive affect after controlling for coping strategies. Importantly, this result supports providing interventions that promote more adaptive emotional self-regulation strategies where high levels of negative illness related emotional impact levels are identified among individuals presenting with HCV.

6.8 General Comments

Results reported in Studies 1.1 and 1.2 suggest that clinicians and researchers should consider the role of illness perceptions and coping strategies in predicting adjustment outcomes among individuals living with HCV. Such considerations could incorporate the design of clinical interventions and research models that focus on improving the adjustment, and therefore the quality of life of individuals diagnosed with HCV, and related chronic illnesses. Both illness perception components and coping strategies predicted physical and psychosocial adjustment among a cohort of individuals with HCV regardless of their respective order of entry into predictive models. Further, as reported in Study 1.1, coping strategies mediated the relationship of some but not all of the relationships between illness perceptions and physical and psychosocial adjustment. Taken together, these results partially confirm the utility of the SRM to identify important links between illness perceptions, coping and adjustment within the context of HCV, including supporting the theoretical considerations related to the role of coping in mediating relations between illness perceptions and health related outcomes outlined in earlier SRM literature (Leventhal et al., 1980).

The following chapter reports on a longitudinal design employed to investigate whether illness perceptions and coping strategies (i.e., SRM) and benefit finding are able to predict biomedical treatment outcomes in HCV. Study 2.1 assessed the efficacy of illness perceptions and coping strategies to predict HCV treatment outcomes after first controlling for biomedical, clinical and behavioural markers that have been utilised in previous HCV treatment research (Lee & Abdo, 2003; Shiffman et al., 2004). Study 2.2 investigated whether benefit finding could predict HCV treatment response after controlling for SRM features

and biomedical, clinical and behavioural variables identified in the first analysis as significant predictors of HCV treatment response. Finally, no previous published research has investigated in a single study whether depression, physical health markers as outlined in Chapter 5, life satisfaction, and positive affect adjustment variables could predict HCV treatment response after controlling for clinical, behavioural and demographic markers. This gap in the literature provided an opportunity to extend the investigations reported in Studies 1.1, 1.2, 2.1, and 2.2, and conduct a further investigation (Study 2.3) to assess whether these variables could establish similar links to HCV treatment response outcomes reported in earlier studies.

Chapter 7

Study 2.1-Illness Perceptions, Coping and Treatment Outcomes in Hepatitis C

7.1 Introduction

The results from Studies 1.1 and 1.2 reported in Chapter 6 demonstrated the efficacy of illness perceptions and coping, to predict physical and psychosocial adjustment regardless of order of entry into predictive models. Benefit finding also predicted psychosocial adjustment outcomes among individuals with HCV (Study 1.1). Further, coping and benefit finding mediated relationships between illness perceptions and physical and psychosocial adjustment measures (Study 1.1). Taken together, these data suggest that the assessment of cross-sectional models reported in Studies 1.1 and 1.2 demonstrated the utility of an expanded SRM to predict physical and psychosocial adjustment within the novel area of HCV. Further, results reported in Study 1.1 identified the role of coping to mediate relations between illness perception components and adjustment, are consistent with the expected interrelations between illness perceptions, coping and health related outcomes reported in earlier SRM literature (Leventhal et al., 1980).

There is a wealth of literature that has confirmed demographic and clinical markers as reliable predictors of biomedical outcomes among individuals undertaking treatment for their HCV (Chen & Morgan, 2006; Lee & Abdo, 2003; Shiffman et al., 2004). Research utilising the SRM has demonstrated its efficacy to predict physical and psychosocial adjustment outcomes across a number of forms of chronic illness (Boddington et al., 2002; Cartwright & Lamb, 1999; Heijmans, 1998; Heijmans, 1999; Helder et al., 2002; Horne et al., 2001; Horne & Weinman, 2002; Kemp et al., 1999; Moss-Morris et al., 2002; Rees et al., 2001; Scharloo et al., 1998; Schiaffino & Cea, 1995; Steed et al., 1999; Theunissen & de Ridder,

2001). The data reported in Studies 1.1 and 1.2 has confirmed the utility of the SRM to predict psychological and physical health in HCV prior to treatment. To date however, few studies have investigated whether the SRM could predict biomedical treatment outcomes in chronic disease conditions. For example, Chilcot et al. (2011) investigated whether illness perceptions predicted survival rates among a cohort of individuals with end stage renal disease. Results of this study identified the important role of perceptions related to treatment control as a predictor of survival after controlling for a number of clinical covariates such as depression, medical comorbidity, age in years, and two renal specific medical markers, serum albumin and haemoglobin levels (Chilcot et al., 2011). Similarly, Paddison et al. (2008) conducted a study that investigated the relative contributions of illness perception components to explaining variance in metabolic control and quality of life among a cohort of individuals living with type 2 diabetes. Poor metabolic control is associated with an increased risk of diabetes related complications (Paddison et al., 2008). Findings indicated that illness perceptions related to shorter illness timeline and greater negative illness related consequences predicted poor metabolic control status after controlling for clinical co-variables, length of time since first diagnosis, body mass index, and type of treatment regimen (insulin or no insulin) (Paddison et al., 2008). Taken together the results reported in Chilcot et al. (2011) and Paddison et al. (2008) demonstrate the important role of illness perceptions in predicting biomedical outcomes over and above the contributions of clinical, behavioural and demographic markers.

To date, no published research has investigated whether illness perceptions and coping strategies can predict HCV treatment response after controlling for biomedical, clinical and behavioural markers that have been utilised in previous

HCV research (Lee & Abdo, 2003; Shiffman et al., 2004). Similar to the approach of Chilcot et al. (2011) and Paddison et al. (2008), the present study investigated whether illness perceptions and coping would predict HCV treatment response (measured at 4, 8, and 12 weeks post-commencement of HCV treatment) after first controlling for a number of biomedical, clinical and behavioural markers utilised in previous HCV biomedical treatment prediction research (Lee & Abdo, 2003; Shiffman et al., 2004). For example, Lee & Abdo (2003) identified important links between a number of pre-HCV treatment bio-medical, clinical and behavioural markers included in Study 2.1, and HCV treatment response measured at 12 weeks. Further, HCV genotype 1, age in years, absence of cirrhosis of the liver, gender and patient body weight have all been identified as important predictors of HCV treatment response (Lee & Abdo, 2003). In line with results reported in Study 1.1 and 1.2, and in previous related research (Chilcot et al., 2011; Paddison et al., 2008), it was hypothesised that illness perceptions and coping would predict HCV treatment response after controlling for bio-medical, clinical and behavioural markers.

7.2 Method

7.2.1 Participants

The first pre-treatment survey was completed by 126 individuals with HCV who were recruited via the study website. Out of this cohort, 32 participants completed the second survey post-commencement of HCV treatment. Table 7.1 summarises biomedical, clinical, behavioural and demographic information.

Table 7.1

Biomedical, Demographic, behavioural and clinical data (N = 32)

Characteristic	<i>N</i>	(%)	<i>M</i>	<i>SD</i>
Age			43.3	13.5
Weight (KG)			78.6	16.1
Gender				
Male	13	40.6		
Female	19	59.4		
Treatment adherence	30	93.8		
IV drug use	11	34.4		
Cirrhosis (<i>n</i> = 23)	7	30.4		
Genotype 1 (<i>n</i> = 26)	14	53.8		
Previous HCV treatment	8	25.0		
Medical comorbidity	12	37.5		
Recreational drugs	7	21.9		
Alcohol use	8	25.0		
Smoking tobacco	10	31.3		
Mental health condition	7	21.9		

7.2.2 Measures

Biomedical, Clinical, behavioural and demographic information – Time 1

As outlined in greater detail in chapter 5, participants at Time 1 responded to specific questions related to age, weight, HCV genotype, gender, and most likely route of HCV infection. They also provided Time 1 yes/no responses to biomedical, socio-demographic and clinical questions related to: (1) cirrhosis of

the liver, (2) other medical conditions, (3) use of recreational drugs, (4) consumption of alcohol, (5) smoking cigarettes, (5) mental health condition/s, and (6) previous treatment for Hepatitis C.

Illness perceptions

Illness perceptions were measured using the Brief Illness Perception Questionnaire (BIPQ: Broadbent et al., 2006) as described in chapter 5.

Coping

Coping was measured by the Brief COPE (Carver, 1997) as outlined in chapter 5).

Outcome Assessment and Adherence to medication – Time 2

HCV treatment response was the outcome measure evaluated at Time 2 (post commencement of HCV treatment). Additionally, a single question related to treatment adherence was also measured at Time 2. Specific details related to both the HCV treatment response questions and treatment adherence question are described in greater detail in chapter 5.

7.2.3 Procedure

Recruitment strategies for Time 2 were identical to those reported for the previous cross-sectional studies. Participants were contacted by email three months post commencement of HCV treatment and were invited to complete a second online survey questionnaire (Time 2). At Time 2 they responded to questions related to HCV treatment outcome, and to treatment adherence relevant to the treatment period. The Time 2 online survey took between 5 and 10 minutes to complete.

7.2.4 Statistical Analysis

An alpha level of .05 was utilised to determine statistical significance. Due to attrition between Time 1 ($n = 126$) and Time 2 ($n = 32$), independent samples t-tests, chi-square analyses and Fisher's exact tests were performed to assess for differences in biomedical, clinical, behavioural, and demographic characteristics (refer Table 7.1), between participants who completed the post-treatment questionnaire and those who did not. The only significant result to emerge was age in years; those who completed the post-treatment questionnaire ($M = 46.98$ years, $SD = 13.55$) were significantly older than participants who only completed the pre-treatment questionnaire ($M = 41.58$ years, $SD = 11.12$), $t(51) = 2.07$, $p = .04$.

7.2.5 Results

Differences in Treatment Response in Biomedical, Clinical, Behavioural and Demographic Markers.

Independent t-tests, chi-square analyses and Fisher's exact tests were used to assess differences in the variables of interest as a function of treatment response. Results revealed significant differences between treatment responders and non-responders related to use of recreational drugs (Fisher's exact test $p < .05$) and the presence of a mental health condition (Fisher's exact test $p < .05$). There were no significant differences between responders and non-responders as a function of treatment adherence (Fisher's exact test $p > .05$), gender ($\chi^2(1, 32) = .00$, $p > .05$), IV drug use transmission ($\chi^2(1, 32) = .00$, $p > .05$), cirrhosis of the liver (Fisher's exact test $p > .05$), HCV Genotype 1 ($\chi^2(1, 26) = 2.59$, $p > .05$), previous HCV treatment (Fisher's exact test $p > .05$), reported medical comorbidity ($\chi^2(1, 32) = 1.88$, $p > .05$), recent alcohol use (Fisher's exact test $p > .05$), or regular cigarette

smoking (Fisher's exact test $p > .05$). Treatment non-responders were not different in age ($M = 42.84$ years, $SD = 12.48$) from treatment responders ($M = 43.73$ years, $SD = 14.91$), $t(30) = -.19$, $p = .85$. Treatment non-responders did not differ in weight ($M = 78.35$ kg, $SD = 16.58$) from non-responders ($M = 78.80$ kg, $SD = 16.03$), $t(30) = 0.08$, $p = .94$.

Treatment Responders vs. Non-Responders: Illness Perceptions and Coping

To investigate differences in illness perception components and coping strategies as a function of treatment response, a multivariate analysis of variance (MANOVA) was performed. The eight illness perception components were included (illness consequence, illness timeline, personal control, treatment control, illness identity, illness concern, illness coherence, and emotional response), along with adaptive and maladaptive coping strategies. Table 7.2 presents descriptive statistics, univariate F-values and effect sizes for treatment non-responders versus treatment responders on each of the dependent variables. Overall, only treatment control demonstrated a significant association with treatment response such that treatment responders reported greater treatment control than did non-responders.

Table 7.2

Means and standard deviations for the illness perception variables and coping strategies as a function of treatment response

<i>Variable</i>	No Treatment Response (<i>n</i> = 17)		Treatment Response (<i>n</i> = 15)		Univariate		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>F</i>	<i>P</i>	<i>Eta</i>
Illness consequence	6.24	1.95	5.73	2.71	0.37	.55	.01
Illness timeline	6.53	2.15	5.00	3.18	2.59	.12	.08
Personal Control	4.59	2.60	4.00	2.51	0.42	.52	.01
Treatment Control	6.35	1.69	7.87	1.64	6.55	.02	.18
Illness identity	5.65	2.34	4.73	2.60	1.09	.30	.04
Illness concern	7.71	1.90	7.73	2.58	0.00	.97	.00
Illness coherence	6.42	2.37	7.53	1.68	2.32	.14	.07
Emotional response	5.88	2.89	5.53	3.07	0.11	.74	.00
Adaptive coping	45.41	12.26	46.47	6.10	0.09	.77	.00
Maladaptive coping	19.07	6.61	17.07	3.61	1.08	.31	.04

Multivariate Prediction of Treatment Response

A logistic regression was performed to assess whether treatment response could be independently predicted by each of the variables found to differentiate responders from non-responders as described above (refer Table 7.3). Accordingly, mental health condition, substance use and treatment control were entered into the regression model. The full model containing the three predictor variables was statistically significant, $\chi^2(3, N = 32) = 18.73, p < .001$. The logistic model overall

explained between 44% (Cox and Snell R square) and 59% (Nagelkerke R squared) of the variance in treatment response outcomes, and correctly classified 84% of the cases. Table 7.3 indicates that all three of the predictor variables made individual and statistically significant contributions to the prediction of treatment response outcomes. More specifically, at pre-treatment the presence of a comorbid mental health condition, substance use, and a stronger perception of the effectiveness of HCV treatment uniquely predicted treatment response.

Table 7.3

Results of logistic regression for predicting treatment response in patients with HCV

						95% CI for Exp(B)	
	B	S.E.	Wald	P	Exp(B)	Lower	Upper
Recreational Drugs	3.75	1.69	4.93	.03	42.50	1.55	1162.22
Mental Health Condition	3.06	1.42	4.64	.03	21.22	1.32	341.89
Treatment Control	.80	.36	4.95	.03	2.22	1.10	4.49
Constant	-7.04	2.83	6.17	.01	.001		

7.3 Discussion

Results of Study 2.1 demonstrated the efficacy of the illness perception of treatment control measured at Time 1 to predict HCV treatment response measured at Time 2 after controlling for clinical, behavioural and demographic variables measured at Time 1. Specifically, perceptions related to a greater belief in the efficacy of HCV treatment predicted treatment response (i.e., nil detection of HCV following milestone blood tests). These results are consistent with Chilcot et al. (2011) who demonstrated that treatment control predicted survival rates among individuals with end stage renal disease after controlling for relevant clinical markers. Further, mental health comorbidity and use of recreational drugs made unique and significant contributions to the prediction of HCV treatment response, such that the presence of mental health comorbidity and the use of recreational drugs predicted a more favourable treatment response. Despite the relatively counter-intuitive direction of these results, a few studies that have investigated the role of recreational drug use and the presence of mental health comorbidity in accounting for variance in HCV treatment response outcomes have identified comparable treatment response outcome rates between recreational drug users, and individuals reported mental health comorbidity compared with non-drug using cohorts and individuals not reporting mental health co-morbidity (Edlin, 2002; Liu et al., 2014; Sylvestre, 2002). Further, other studies have directly identified links between recreational drug use during HCV treatment and improved HCV treatment response outcomes (Costiniuk, Mills, & Cooper, 2008; Sylvestre, Clements, & Malibu, 2016). A related study did not identify any links between recreational drug use whilst receiving HCV treatment and treatment response (Liu et al., 2014). Relevant to mental health comorbidity, improved HCV response outcomes was

associated with the early identification and appropriate treatment of depression among individuals presenting for HCV treatment (Sockalingam & Abbey, 2009). It may be that particular recreational drugs may have specific effects that ameliorate, to a degree some of the potentially negative HCV treatment side-effects that can be experienced during treatment, along with the positive psychological benefits associated with psychotropic medications prescribed to address mental health conditions, taken together may potentially contribute to improved HCV treatment response.

Contrary to hypothesised expectations there were no significant differences between treatment non-responders and treatment responders on the adaptive and maladaptive coping strategies. Therefore, adaptive and maladaptive coping strategies were not entered into subsequent logistic regression analysis.

The SRM proposes that when individuals become aware of an illness experience they construct a number of illness related perceptions in an attempt to create understanding of what is happening. These illness perceptions are then proposed to drive coping behaviours with the aim of attaining favourable illness related outcomes (Broadbent et al., 2006; Leventhal et al., 1980). Within the present study the data highlighted the important role of treatment control within the HCV treatment predictive framework. In addition to the number of clinical markers that have been identified in HCV literature as contributing to the prediction of treatment response, such as particular HCV genotype and BMI (Chen & Morgan, 2006; Lee & Abdo, 2003; Shiffman et al., 2004), a significant factor that contributes to this outcome is the ability to effectively engage in self-management behaviours whilst on treatment (Shiffman et al., 2004). For example, despite no difference in Study 2.1 between responders and non-responders as a

function of HCV medication adherence, adherence to HCV anti-viral regimens often requires self-administration of anti-viral medications on a daily basis and has been linked to treatment response in a number of studies (Lee & Abdo, 2003; Shiffman et al., 2004). Perhaps the low sample size ($n = 32$) reported in Study 2.1 contributed to these non-significant findings related to medication adherence compared to other studies that reported larger sample sizes and identified links between medication adherence and HCV treatment response (Lee & Abdo, 2003; Shiffman et al., 2004). Based on the findings reported in the majority of HCV treatment studies that have included measuring links between medication adherence and HCV treatment response (Lee & Abdo, 2003; Shiffman et al., 2004), in partly accounting for the results reported for treatment control reported in Study 2.1, it may be therefore, that levels of motivation to engage with required medication regimens are likely to be influenced by perceptions of the efficacy of the prescribed treatments. Therefore greater treatment control perceptions would potentially have a significant influence on adherence behaviours. In other words, an individual might be unlikely to adhere to the requirements associated with HCV treatment if they held low perceptions related to treatment control.

The SRM assumes that the cognitions associated with individual illness perceptions are amenable to psychological intervention (Chilcot et al., 2011; Hagger & Orbell, 2003; Leventhal et al., 1980). The results of Study 2.1 highlight the potential importance of assessing the illness perceptions of individuals preparing for HCV treatment, and implementing psychological interventions that address maladaptive illness perceptions and strengthen more adaptive illness perceptions with the aim of creating optimal psychological platforms prior to the commencement of HCV treatment. Overall, the results of the present study support

previous research conducted within the context of chronic disease that have demonstrated the efficacy of illness perceptions related to treatment control to predict treatment outcomes (Chilcot et al., 2011; Rutter & Rutter, 2002; Steed et al., 1999).

7.4 General Comments

In summary, the results of Study 2.1 further support the inclusion of illness perceptions as an important factor in predicting HCV treatment response (Shiffman et al., 2004). Study 2.2, expanded on the results of Study 2.1, and tested the efficacy of benefit finding to predict HCV treatment response after controlling for mental health conditions, recreational drugs, and treatment control. The primary rationale for the order of entry of psychological variables investigated in Studies 2.1 and 2.2 was based on SRM theoretical considerations (Leventhal et al., 1980). Therefore, Study 2.1 investigated the traditional features of the SRM, illness perceptions and coping to predict HCV treatment response after first controlling for the contributions of clinical, behavioural, and demographic markers. In line with one of the primary aims of the present thesis, Study 2.2 provided the opportunity to extend the utility of the traditional features of the SRM to predict HCV treatment response, and assess whether an expanded model, including benefit finding could make significant contributions to the prediction of HCV treatment response beyond traditional features of the SRM and other relevant clinical, behavioural and demographic variables.

Study 2.2 - Biomedical Markers, Illness Perceptions, Benefit Finding and Hepatitis C Treatment Outcomes

7.5 Introduction

In line with one of the primary aims of the present thesis, to assess whether an expanded SRM could predict HCV treatment response, Study 2.2 investigated whether benefit finding predicted HCV treatment response after controlling for comorbid mental health conditions, recreational drug use, and illness perceptions related to treatment control. The use of recreational drugs and reported mental health comorbidity along with treatment control were included in the present study due to their respective significant associations with the treatment response criterion variable reported in Study 2.1.

As reported in Study 1.1, benefit finding predicted psychosocial adjustment outcomes among individuals with HCV. These results are consistent with a number of studies across chronic health conditions that have identified the role that benefit finding can have in predicting psychosocial adjustment (Helgeson et al., 2006). The role of benefit finding was not associated with physical health adjustment prior to HCV treatment in the present thesis. However, a number of chronic disease studies have identified the efficacy of benefit finding to predict both physical health adjustment and biomedical treatment outcomes (de Ridder, 2008). To date, no published research has focussed on whether benefit finding could predict HCV treatment response within an expanded SRM, which provided the impetus for Study 2.2.

It was hypothesised that benefit finding would predict HCV treatment response over and above the contributions of treatment control, mental health comorbidity and recreational drug use.

7.6 Method

The participants, measures and procedure are the same as for Study 2.1

7.6.1 Results

To investigate differences in treatment control and benefit finding as a function of treatment response, a multivariate analysis of variance (MANOVA) was performed. Treatment control and benefit finding demonstrated a significant association with treatment response. Table 7.4 presents descriptive statistics, univariate F-values and effect sizes for treatment non-responders versus treatment responders on each of the dependent variables included in the present study, treatment control and benefit finding.

Table 7.4

Means and standard deviations for the illness perception variable and benefit finding as a function of treatment response

<i>Variable</i>	No Treatment Response (<i>n</i> = 17)		Treatment Response (<i>n</i> = 15)		Univariate		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>F</i>	<i>P</i>	<i>Eta</i>
Treatment control	6.35	1.69	7.87	1.64	6.55	.02	.18
Benefit finding	62.47	33.82	41.33	19.72	4.50	.04	.13

Multivariate Prediction of Treatment Response

A logistic regression (refer Table 7.5) assessed whether treatment response could be independently predicted by each of the variables found to differentiate responders from non-responders as described above. Accordingly, mental health condition, substance use, treatment control and benefit finding were entered into the regression model. The full model containing the four predictor variables was statistically significant, $\chi^2(4, N = 32) = 24.20, p < .001$. The logistic model overall explained between 53% (Cox and Snell R square) and 71% (Nagelkerke R squared) of the variance in treatment response outcomes, and correctly classified 84% of the cases. Table 7.5 indicates that treatment control and benefit finding were significant predictors of treatment response. The presence of a comorbid mental health condition, and recreational drug use, failed to contribute to the model.

Table 7.5

Results of logistic regression for predicting treatment response in patients with HCV.

						95% CI for Exp(B)	
	B	S.E.	Wald	P	Exp(B)	Lower	Upper
Recreational Drugs	4.12	2.22	3.45	.06	61.63	.79	4784.11
Mental Health Condition	2.83	1.55	3.32	.07	16.88	.81	352.35
Treatment Control	1.22	.50	5.97	.02	3.40	1.23	9.03
Benefit Finding	-.05	.03	4.08	.04	.95	.91	.99
Constant	-7.23	3.22	5.06	.02	.001		

7.7 Discussion

Study 2.2 investigated whether benefit finding predicted treatment response over and above the contributions of mental health comorbidity, recreational drug use and treatment control within the context of an expanded SRM. These three predictor variables were included as covariates in the present study following their association with in treatment response as confirmed in Study 2.1.

Consistent with results reported Study 2.1, treatment control made a significant individual contribution to the prediction model. Illness perceptions related to treatment control (i.e. “*how much do you think your treatment can help your HCV?*”) predicted treatment response. Contrary to Study 2.1, mental health comorbidity and the use of recreational drugs did not make a significant contribution to the predictive model. These results are inconsistent with previous

studies that have demonstrated the efficacy of clinical and behavioural markers such as reported in the present analysis, mental health co-morbidity and the use of recreational drugs, to predict HCV treatment response (Chen & Morgan, 2006; Lee & Abdo, 2003; Shiffman et al., 2004).

Counter to expectations, lower benefit finding predicted HCV treatment response. No previous published research has investigated whether benefit finding predicted biomedical HCV treatment response outcomes and therefore comparison of the data reported here and current empirical work is not possible. The exact reason for these results is unclear. However, it is important to note that similar counter-intuitive results have been reported in other chronic disease studies related to benefit finding, biomedical treatment outcomes, and physical and psychosocial adjustment (de Ridder et al., 2008; McMillen & Fisher, 1998; Helgeson et al., 2006). For example, in a study conducted among individuals who had recently been diagnosed up to four months previously with breast cancer, greater benefit finding predicted high levels of depression at 3 - 9 month follow up (Tomich & Helgeson, 2004). However, in a related study, individuals who had been diagnosed with breast cancer 3-12 months previously, greater benefit finding predicted decreased depression at 4-7 year follow up (Carver & Antoni, 2004). Relevant to the present thesis, it could be that the time period between the measurement of benefit finding and collection of outcome data could in some part explain the more counter-intuitive results reported here (de Ridder et al., 2008). As reported in the present thesis, collection of treatment outcome data similar to the Tomich and Helgeson (2004) study occurred at a relatively shorter follow up period, with similar reporting of predictive relations between benefit finding and outcome. Further, Stanton and Bower (2006) in a study conducted among cancer survivors

suggested that relatively earlier measurement of benefit finding could represent a type of avoidance behaviour. Additionally, Tomich and Helgeson (2004) suggested that earlier collection of benefit finding data may be qualitatively different from benefit finding data collected at later follow up time periods. However, other related chronic disease research found that benefit finding interventions conducted in shorter time periods following diagnosis were associated with more favourable outcomes (Antoni et al., 2001; de Ridder et al., 2008). Future studies that explore the relationship between benefit finding and treatment response outcomes among individuals with HCV may benefit from considering the findings of these studies when designing research models (Antoni et al., 2001; Carver & Antoni, 2004; de Ridder et al., 2008; Stanton & Bower, 2006; Tomich & Helgeson, 2004).

7.8 General Comments

The results of Study 2.2 support the utility of an expanded SRM to predict HCV treatment response. Further, consistent with results reported in Study 2.1, perceptions related to HCV treatment control predicted treatment response rates. As reported previously, these results are supported by other studies that have demonstrated the efficacy of illness perceptions to predict physical and psychosocial adjustment and biomedical treatment outcomes across varied areas of chronic disease (Chilcot et al., 2011; Fortune et al., 2002; Heijmans, 1999; Helder et al., 2002; Rutter & Rutter, 2002; Scharloo et al., 2000; Steed et al., 1999). Interestingly, in comparison to Study 2.1, after including benefit finding into the prediction model the contributions of reported mental health condition and the use of recreational drugs were no longer significant.

In Study 2.3 the four criterion variables utilised in the cross-sectional studies reported in Study 1.1 and 1.2 were employed as predictors of HCV

treatment response after controlling for use of recreational drugs and reported mental health condition. As reported previously in Study 2.1, use of recreational drugs and reported mental health condition were the only clinical and behavioural variables to demonstrate significant associations with the treatment response criterion. A limitation of the results reported in Study 2 was that those who completed surveys at Time 2 were older than the mean age of participants who completed surveys at Time 1. Therefore, these results should be interpreted with some caution, as they may not be generalisable to younger individuals.

Study 2.3 - Depression, Physical Health, Life Satisfaction, Positive Affect and Treatment Response Outcomes in HCV

7.9 Introduction

Studies 2.1 and 2.2 identified a key role for the illness perception, treatment control in the prediction of HCV treatment response after controlling for the use of recreational drugs and reported mental health comorbidity, which were controlled after demonstrating significant associations with the HCV treatment response criterion variable. Further, benefit finding predicted HCV treatment response after controlling for the recreational drug use and mental health condition covariates, albeit in a counter-intuitive way. Lower benefit finding predicted HCV treatment response. The primary aim of Study 2.3 was to investigate whether the four criterion variables included in Studies 1.1 and 1.2 could predict HCV treatment response after controlling for the contributions of recreational drug use and reported mental health condition.

A comparatively limited number of studies that have assessed whether depression predicted biomedical treatment outcomes in chronic disease have produced relatively mixed results (Chilcot et al., 2011; Lopes et al., 2002). For example, Chilcot et al. (2011) conducted a study to assess whether depression predicted survival rates among individuals with end stage renal disease. In this study, depression failed to predict survival rates (Chilcot et al., 2011). However, in a related study, Lopes et al. (2002) found that depression predicted mortality and hospitalization rates among patients with kidney disease who were undergoing haemodialysis treatment. To date, no identified published research that utilised a longitudinal research design has investigated the potential role for depression to

independently predict HCV treatment response. This gap in the literature provided an opportunity to extend the investigations related to whether an expanded SRM could explain variance in HCV treatment response as reported in Studies 2.1 and 2.2, and assess the efficacy of depression to predict treatment response among a cohort of individuals undergoing HCV treatment. It should be noted, in the present study, mental health condition was removed from the predictive model due to its high correlation with depression.

There is a wealth of research that has investigated the role of biomedical markers in predicting HCV treatment response outcomes (Shiffman et al., 2004). In assessing the efficacy of physical health to predict HCV treatment response, many studies have included various determinants of overall physical health, such as obesity and the presence of liver pathology (Lee & Abdo, 2003; Shiffman et al., 2004). No published studies to date have assessed self-reported physical health (physical functioning, role functioning, general health perceptions, and the experience of bodily pain) as a predictor of HCV treatment response. Study 2.3 provided an opportunity to assess the role of physical health to predict HCV treatment response. Similarly, no published research to date has investigated whether self-reported life satisfaction and positive affect could predict HCV treatment response. This gap in the literature provided an opportunity to assess the efficacy of life satisfaction and positive affect as broad measures of quality of life to predict HCV treatment response

The following predictions were made based on previous work and theory:

(1) After controlling for the use of recreational drugs, depression was expected to emerge as a strong predictor of HCV treatment response.

(2) Physical health was expected to predict HCV treatment response after accounting for the contributions of recreational drug use and reported mental health condition.

(3) Life satisfaction and positive affect were expected to predict HCV treatment response after controlling for recreational drug use and mental health condition.

7.10 Method

Details of the participants and procedure are described in Studies 2.1 and 2.2. The measures are described in Chapter 5.

7.10.1 Results

Fisher's exact tests were used to assess differences in the variables of interest as a function of treatment response. As reported in Study 2.1, results revealed significant differences between treatment responders and non-responders on recreational drug use (Fisher's exact test $p < .05$) and the presence of a mental health condition (Fisher's exact test $p < .05$) and so these variables were retained in the analyses.

To investigate differences in depression, physical health, life satisfaction, and positive affect as a function of treatment response, a multivariate analysis of variance (MANOVA) was performed. Table 7.6 presents descriptive statistics, univariate F-values and effect sizes for treatment non-responders versus treatment responders on each of the dependent variables included in the present analysis. Overall, only depression demonstrated a significant association with treatment response ($p = .024$).

Table 7.6

Means and standard deviations for dependent variables as a function of treatment response

<i>Variable</i>	No Treatment Response (<i>n</i> = 17)		Treatment Response (<i>n</i> = 15)		Univariate		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>F</i>	<i>p</i>	<i>Eta</i>
Depression	18.24	11.88	10.13	6.07	5.66	.024	.159
Physical health	48.90	26.32	58.13	18.32	1.29	.265	.041
Life satisfaction	17.94	6.81	17.97	6.04	.001	.979	.000
Positive affect	15.06	4.12	12.93	4.22	2.08	.160	.065

Multivariate Prediction of Treatment Response

A logistic regression was performed to assess whether treatment response could be independently predicted by variables that had been found to differentiate responders from non-responders (refer to Table 7.7). Only depression demonstrated significance, and therefore was the only variable to be entered into the regression model along with use of recreational drugs.

The full model containing the four predictor variables was statistically significant, $\chi^2(2, N = 32) = 11.51, p = .003$. The logistic model overall explained between 30% (Cox and Snell R square) and 40% (Nagelkerke R squared) of the variance in treatment response outcomes, and correctly classified 69% of the cases.

Table 7.7 indicates that depression was the only predictor of treatment response.

Use of recreational drugs failed to add to the predictive model.

Table 7.7

Results of logistic regression for predicting treatment response in patients with HCV

						95% CI for Exp(B)	
	B	S.E.	Wald	P	Exp(B)	Lower	Upper
Recreational Drugs	1.63	1.22	1.80	.18	5.11	.472	55.41
Depression	-.109	.053	4.13	.04	.897	.808	.996
Constant	1.145	.890	1.65	.198	3.143		

7.11 Discussion

In Study 2.3, depression emerged as a predictor of treatment response after controlling for the contributions of the use of recreational drugs. Further, these results are consistent with the findings in a related chronic disease study reported by Lopes et al. (2002) in which depression predicted mortality and hospitalization rates among patients who were undergoing haemodialysis treatment related to their kidney disease, and give support for including comprehensive assessment of mood among individuals preparing for HCV treatment.

Contrary to expectations, life satisfaction, positive affect and physical health were not associated with treatment response, and therefore these variables were not investigated further. Past research has identified a significant role for a number of HCV biomedical markers considered to be determinants of physical

health, including obesity and cirrhosis of the liver, in predicting HCV treatment response (Shiffman et al., 2004). This provided the primary rationale to assess the efficacy of physical health related to physical functioning, role functioning, reported bodily pain and general health perceptions to predict HCV treatment response. Further, life satisfaction and positive affect failed to meet the criteria for entry into logistic regression analysis following non-significant results of a MANOVA. However, life satisfaction and positive affect accounted for adjustment outcomes reported in Study 1.1 and 1.2. This provided support for their inclusion in the present longitudinal analysis.

7.12 General Comments

In Study 2.3 pre-treatment depression was identified as a significant predictor of HCV treatment response. This result has important implications for individuals undergoing assessment and treatment for HCV from a wider psychosocial level. Depression should thus be included in future related HCV treatment response studies to follow up the results reported in the present study.

Chapter 8

General Discussion

8.1 Overview

In summary, the investigations presented in the present thesis have established several novel and important findings:

1. Features of the SRM, illness perceptions and coping strategies, predicted physical and psychosocial adjustment among individuals with HCV.
2. As part of an expanded SRM, benefit finding predicted psychosocial adjustment after first controlling for the contributions of illness perception components and coping strategies.
3. Coping strategies and benefit finding in some, but not all cases mediated the relationships between illness perceptions and physical and psychosocial adjustment.
4. Stronger treatment control perceptions, greater mental health comorbidity and recreational drug use predicted HCV treatment response. Lower reporting of benefit finding predicted HCV treatment response. Coping strategies failed to contribute to the prediction model among this same HCV treatment cohort.
5. Lower pre-treatment depression predicted HCV treatment response after first controlling for the contributions of recreational drug use.

8.2 Relations Between Illness Perceptions, Coping, Benefit Finding, and Physical and Psychosocial Adjustment – Review of Cross-Sectional Studies.

Studies 1.1 and 1.2 confirmed illness perceptions, coping strategies and benefit finding were linked to psychosocial adjustment indices of depression, life satisfaction and positive affect. Similarly, illness perceptions and coping strategies

predicted physical health adjustment. However, benefit finding did not predict physical health. These results are somewhat consistent with a number of other chronic disease studies that have demonstrated; (1) the efficacy of benefit finding to predict psychosocial adjustment, and (2) the efficacy of various combinations of traditional SRM features to predict both physical and psychosocial adjustment (Broadbent et al., 2015; de Ridder et al., 2008; Hagger & Orbell, 2003; Helgeson et al., 2006). Interestingly, other chronic disease studies have not reliably demonstrated coping as a predictor of physical and psychosocial adjustment (Hagger & Orbell, 2003; Heijmans, 1999; Rutter & Rutter, 2002; Steed et al., 1999), and there has been mixed reports of benefit finding predicting physical adjustment (de Ridder et al., 2008). The inconsistent results between HCV and other chronic disease conditions may be explained by the following; (1) a lack of consistency regarding versions of illness perception questionnaires used across studies reported in Studies 1.1 and 1.2. For example, earlier versions did not include specific illness perception components that have subsequently been included in more recent versions, such as the BIPQ (Broadbent et al., 2006; Weinman et al., 1996). Similarly, there has been a general lack of consistency regarding versions of coping and benefit finding measures used across a number of chronic disease studies, and therefore lack of consistency regarding individual coping and benefit finding items included in these measures, and (2) differences in the manifestation of disease characteristics across the various chronic health conditions reported in Studies 1.1 and 1.2. may have further contributed to variance in the reporting of results between those reported for HCV and other chronic health conditions.

A number of illness perception components and coping strategies made unique and significant contributions to the prediction of physical and psychosocial adjustment in Studies 1.1 and 1.2. Consistent with a number of other chronic disease studies (Broadbent et al., 2015; Rutter & Rutter et al., 2002; Vaughan et al., 2003), personal control made unique and significant contributions to the prediction of depression, physical health, life satisfaction and positive affect, independently and after controlling for the contributions of coping. Important to clinicians providing psychological assessment and interventions to individuals presenting with HCV, these results highlight the important role that increased perceptions related to an individual's perceived personal control over their HCV can have in predicting lower levels of reported depression, higher satisfaction with physical health and better quality of life. However, as reported in Study 1.1, these findings were not consistently reported across other chronic disease studies (Heijmans, 1998; Heijmans, 1999; Scharloo et al., 1998; Helder et al., 2002). It may be that the use of cure/control combining both treatment control and personal control features in a single item in earlier versions of illness perception measures may have contributed to variance in results reported across chronic disease studies regarding the potential effectiveness of personal control to predict physical and psychosocial adjustment.

Similarly, illness identity made unique and significant contributions to depression and physical health adjustment in Studies 1.1 and 1.2. These results are consistent with a number of other chronic disease studies (Broadbent et al., 2015; Daleboudt et al., 2013; Heijmans, 1999; Helder et al., 2002), and indicate that for individuals living chronic disease, including HCV, higher reporting of illness symptoms was associated with lower mood levels, physical functioning and

perceptions related to physical health wellbeing. However, in one chronic disease study, illness identity did not predict either depression or physical health adjustment among a cohort of individuals living with irritable bowel syndrome (Rutter & Rutter, 2002). This result may highlight the role that differences in disease characteristics such as severity, duration and frequency of symptom reporting across different chronic health conditions, such as HCV and irritable bowel syndrome can have in contributing to variance in both physical and psychosocial adjustment outcomes.

Illness coherence and emotional response predicted depression which is consistent with other chronic diseases (Broadbent et al., 2015; Hagger & Orbell, 2003; Joshi et al., 2015). For example, Joshi et al. (2015) identified links between illness coherence, emotional response and depression in sufferers of type 2 diabetes. Higher negative emotional responses predicted higher reporting of depression. Conversely, greater illness understanding predicted lower depression (Joshi et al., 2015). Similarly, as reported here, individuals with a greater understanding of their HCV reported lower depression, whereas individuals reporting a higher negative emotional response to their HCV reported higher depression. In Study 1.2 illness perceptions related to illness coherence and emotional response did not predict depression after controlling for the contributions of coping strategies. It may be that illness coherence and emotional response are relatively weaker predictors of depression among individuals with HCV. Illness identity and personal control both predicted depression independently and after controlling for the contributions of coping strategies. Interestingly, after controlling for coping strategies, emotional response accounted for significant variance in positive affect. Less negative illness related emotional responses to

HCV predicted increased positive affect. Similar findings that identified the important role of emotional response to illness in accounting for variance in quality of life adjustment were reported in a study conducted by Paddison et al. (2008). A lower negative emotional response to the experience of living with chronic type 2 diabetes predicted improved quality of life. Further, in related chronic disease studies important links were identified between emotional response and medication adherence among individuals living with coronary heart disease (Platt, Green, Jayasinghe, & Morrissey, 2014), and in emotional response accounting for variance in physical functioning related to intimacy among a cohort of individuals living with the experience of lupus erythematosus (Daleboudt et al., 2013). These results identify important associations between emotional self-regulation and the subjective experiences of positive mood states among individuals living with HCV and Type 2 diabetes, and medication adherence and physical functioning among individuals living with coronary heart disease and lupus erythematosus, respectively (Daleboudt et al., 2013; Paddison et al., 2008; Platt et al., 2014). However, it should be noted that similar to previous findings reported in Studies 1.1 and 1.2, variability in the inclusion of illness perception components across a number of chronic disease studies, emotional response was not included in an earlier version of the illness perception questionnaire (Weinman, Petrie, Moss-Morris, & Horne, 1996), which may have contributed to the under-reporting of the potential importance of the role of emotional response in predicting physical and psychosocial adjustment in other chronic disease conditions (Fortune et al., 2002; Helder et al., 2002; Rutter & Rutter, 2002; Steed et al., 1999; Vaughan et al., 2003).

Illness timeline predicted life satisfaction independently and after controlling for coping strategies. Perceptions related to a shorter illness timeline predicted higher life satisfaction. In a number of chronic disease studies perceptions related to illness timeline reported in Addison's disease (Heijmans, 199), multiple sclerosis (Vaughan et al., 2003), rheumatoid arthritis, psoriasis, and chronic pulmonary disease (Scharloo et al., 1998), have identified predictive links between longer illness duration and higher reporting of depression. It may be that the link between shorter illness duration perceptions and greater life satisfaction may be related to the treatment cure that is potentially available for HCV which sets HCV apart from the majority of other chronic disease conditions where the focus is more on longer term symptom management and quality of life issues. This explanation may provide a partial explanation for the links between illness timeline and depression reported in other chronic disease conditions where a medical cure is not available. For example, it may be that in conditions where a treatment cure is not available such as multiple sclerosis a sense of hopelessness or resignation may arise regarding the progressive nature of their condition, which may then increase the risk of symptoms associated with depression (Vaughan et al., 2003).

As reported in Studies 1.1 and 1.2, illness consequence, treatment control, and illness concern did not make significant contributions to the prediction of any of the four criterion variables, depression, physical health, life satisfaction or positive affect. Firstly, higher reported illness related seriousness or consequence and illness concern have accounted for variance in depression and physical health adjustment outcomes in a number of chronic disease studies (Broadbent et al., 2015; Fortune et al., 2002; Hagger & Orbell, 2003; Heijmans, 1998; Heijmans, 1999; Petriček et al., 2009; Rutter & Rutter, 2002; Vaughan et al., 2003;

Westbrook, Maddocks, & Andersen, 2016). Chronic health conditions by their nature are often associated with significant negative consequences and greater illness related concern which may contribute to lower physical functioning and mood disturbance (Broadbent et al., 2015; Fortune et al., 2002; Hagger & Orbell, 2003; Heijmans, 1998; Heijmans, 1999; Petriček et al., 2009; Rutter & Rutter, 2002; Vaughan et al., 2003; Westbrook et al., 2016). In comparing these findings with those reported for HCV in Studies 1.1 and 1.2, it may be that the idiosyncratic disease characteristics associated with HCV, including a potential treatment cure, result in generally lower perceived negative illness related consequences, and lower levels of illness related concern for individuals living with HCV in comparison to other chronic conditions. Additionally, illness concern was not included in earlier versions of illness perception measures, therefore relatively fewer studies have been conducted that have included the measurement of illness concern in comparison to illness consequence (Broadbent et al., 2015; Hagger & Orbell, 2003; Moss-Morris et al., 2002; Weinman et al., 1996).

Treatment control, did not make significant contributions to any of the criterion measures reported in Studies 1.1 and 1.2. A number of earlier chronic disease studies that utilised illness perception measures identified a role for a combined cure/control variable to account for variance in physical and psychosocial adjustment (Heijmans, 1999; Rutter & Rutter, 2002; Vaughan et al., 2003). Other chronic disease studies did not identify these same predictive links (Heijmans, 1998; Helder et al., 2002). A number of more recent studies that have measured treatment control separately from personal control, and consistent with results reported in Studies 1.1 and 1.2 did not identify a role for treatment control in accounting for variance in physical and psychosocial adjustment (Broadbent et

al., 2015; Rahimi, Baljani, & Zadgasem, 2012; Westbrook et al., 2016). For example, in a study conducted by Rahimi et al. (2012) treatment control did not account for variance in physical and psychosocial adjustment outcomes among individuals with end stage renal disease. Similarly, Westbrook et al. (2016) did not identify a role for treatment control to predict depression among a group of individuals with chronic lymphocytic leukaemia. Further, significant links were identified between treatment control and HCV treatment response reported in Studies 2.1 and 2.2. It may be that treatment cure is less relevant to physical and psychosocial adjustment among a number of chronic diseases including HCV, but more relevant to the prediction of treatment outcomes, such as is found in HCV, where a treatment cure is possible.

Maladaptive coping strategies (i.e., denial, substance use, venting, self-blame, and behavioural disengagement) (Carver, 1997), were associated with physical and psychosocial adjustment among individuals with HCV. Consistent with previous work (Fortune et al, 2002; Helder et al., 2002; Heijmans, 1999; Rutter & Rutter, 2002), greater adoption of maladaptive coping strategies predicted higher depression and poorer physical health. For example, in a study conducted by Helder et al. (2002) among a group of individuals with psoriasis, coping strategies associated with emotional venting accounting for variance in depression, whilst increased adoption of coping strategies associated with behavioural disengagement predicted poorer physical health outcomes. Similarly, greater adoption of coping strategies associated with behavioural disengagement predicted higher depression in individuals with irritable bowel syndrome (Rutter & Rutter, 2002). Further, similar to results in a number of other chronic disease studies (Hagger & Orbell, 2003; Rutter & Rutter, 2002), greater use of adaptive coping

strategies (referring to strategies related to mental disengagement, active coping, use of instrumental and emotional support, positive re-framing, planning, use of humour, acceptance, and use of religion) (Carver, 1997) predicted lower depression, and higher quality of life, as reflected in greater life satisfaction and positive affect ratings. For example, in a study conducted by Rutter & Rutter (2002) greater seeking of emotional support predicted lower depression among individuals living with irritable bowel syndrome. In this same study, greater adoption of coping strategies associated with illness acceptance predicted higher quality of life (Rutter & Rutter, 2002).

Counterintuitively, the data reported in Studies 1.1 and 1.2 revealed maladaptive and active coping strategies were associated with higher life satisfaction and positive affect ratings. As noted, these results may reflect an idiosyncratic picture of living with chronic HCV in comparison to other chronic health conditions, and are worthy of consideration when assessing coping strategies in HCV sufferers. For example, in the face of high levels of HCV symptom reporting individuals may engage with both maladaptive (e.g., substance use) and adaptive coping strategies (e.g., active planning) simultaneously in an attempt to ameliorate their negative experience of HCV related symptoms, and at the same time improve overall quality of life as reflected in higher life satisfaction and positive affect.

Other chronic disease studies that have utilised the SRM have not consistently included coping strategies in their modelling (Broadbent et al., 2015; Hagger & Orbell, 2003). Further, there has been a greater variety of coping measures used in comparison to the relatively more homogenous use of illness perception measures across chronic disease studies that have investigated whether

the SRM could account for physical and psychosocial adjustment (Hagger & Orbell, 2003). These factors may have contributed to greater variability in the reporting of coping strategies in comparison to those that have been reported for illness perceptions (Hagger & Orbell, 2003). Despite the counter-intuitive results reported for maladaptive coping reported in Studies 1.1 and 1.2 in relation to quality of life, maladaptive strategies accounted for significant variance in physical and psychosocial adjustment outcomes independently, and after controlling for illness perceptions. Similarly, adaptive coping strategies predicted life satisfaction and positive affect adjustment. Taken together, these results demonstrate the relative importance of coping strategies in accounting for HCV adjustment in comparison to results reported in a number of other chronic disease studies where coping made less consistent contributions to the prediction of adjustment (Broadbent et al., 2015; Hagger & Orbell, 2003; Heijmans, 1999; Scharloo et al., 1998; Vaughan et al., 2003).

Similar to results reported in a number of other chronic disease studies (Bower et al., 2005; Helgeson et al., 2006; Park et al., 2009; Tennen et al., 1992), greater benefit finding predicted increased quality of life outcomes in Study 1.1. For example, Bower et al. (2005) reported that among women who had been first diagnosed with breast cancer between one to five years previously, greater benefit finding was associated with positive affect. However, in a related study conducted by Tomich and Helgeson (2004) among women who had first been diagnosed with breast cancer four months previously, benefit finding did not predict positive affect adjustment outcomes. Further, as reported in Study 1.1 and consistent with findings reported in Helgeson et al. (2006) benefit finding did not predict physical health adjustment. In contrast, in a study conducted by Luszczynska et al. (2007)

among individuals with human immunodeficiency virus, greater benefit finding predicted better physical health among this cohort of individuals. In accounting for the relative discrepant findings reported in other chronic disease studies reported here in relation to positive affect and physical health, de Ridder et al. (2008) following a review of a number of studies that investigated links between benefit finding and adjustment, found associations between longer time periods of time since initial diagnosis, the provision of benefit finding interventions and greater benefit finding. To assist in explaining any discrepant findings in future HCV studies that investigate links between benefit finding and adjustment, questions related to time since diagnosis and whether individuals had received benefit finding interventions should be included in assessment protocols.

In Study 1.1, greater benefit finding predicted higher depression scores. Similar results were reported by McMillen and Fisher (1998) who suggested that the discovery of meaning and depression may reasonably occur simultaneously among individuals with chronic health conditions such as HCV. Further, in a study measuring benefit finding among a group of women with breast cancer, increased benefit finding predicted higher negative effect (Tomich & Helgeson, 2004). In contrast, greater benefit finding predicted lower depression among a group of individuals living with human immunodeficiency virus (Littlewood et al., 2008). Further, Helgeson et al. (2006) conducted a meta-analytic review to investigate whether benefit finding accounted for physical and psychosocial adjustment among individuals who had experienced adverse events including chronic disease. Overall findings found associations between greater benefit finding and lower depression (Helgeson et al., 2006). Taken together, it may be that for a number of chronic conditions, including HCV, the level of significance reported for associations

between benefit finding and depression may be of greater value than the direction of these predictive links.

As reported in Study 1.1, maladaptive coping mediated the relationships between illness identity and depression and between emotional response and depression, and partially mediated the relationship between illness identity and physical health. These results are partially consistent with mediation tests between illness perceptions, coping strategies and physical and psychosocial adjustment reported by Rutter and Rutter (2002), in which coping mediated some, but not all of the relationships between illness perceptions and adjustment among individuals living with irritable bowel syndrome. Specifically, greater adoption of maladaptive coping strategies associated with behavioural disengagement predicted higher depression (Rutter & Rutter, 2002). Other studies have not found the same efficacy for coping strategies to mediate relations between illness perceptions and adjustment (Hagger & Orbell, 2003; Heijmans, 1998). For example, Heijmans (1998) assessed whether coping mediated relations between illness perceptions and physical and psychosocial adjustment among a cohort of individuals with chronic fatigue syndrome. Results did not establish a role for coping in mediating relations between illness perceptions and adjustment (Heijmans, 1998). Further, relatively few chronic disease studies have included tests that have assessed the efficacy of coping to mediate relations between illness perceptions and adjustment (Broadbent et al., 2015; Hagger & Orbell, 2003). This has been due in part to the more mixed results reported overall for coping in comparison to illness perceptions which has consistently accounted for variance in physical and psychosocial adjustment reported across a number of chronic disease studies (Broadbent et al., 2015; Hagger & Orbell, 2003).

Maladaptive coping strategies predicted depression and physical health adjustment independently, and after controlling for the contributions of illness perceptions reported in Studies 1.1 and 1.2. In comparison, adaptive coping strategies did not make significant contributions to the prediction of depression or physical health in either of these studies and therefore were not entered into tests for mediation. Further, maladaptive coping strategies mediated relationships between illness identity and depression, emotional response and depression, and partially mediated the relations between illness identity and physical health. In contrast to these results, active coping mediated the relationship between cure/control and physical health adjustment reported in Rutter and Rutter (2002). The results reported for HCV in Studies 1.1 and 1.2 may indicate a relatively greater importance regarding the role of maladaptive coping in the prediction and mediation of relations between illness perceptions and adjustment in comparison to adaptive coping strategies, and therefore support providing psychological strategies that seek to modify illness identity and emotional response perceptions, at the same time assisting individuals to adopt more adaptive coping strategies with the aim of improving depression and physical health adjustment.

As reported in Study 1.1, no previous published research as assessed for links between benefit finding and physical and psychosocial adjustment within the context of HCV. Further, relatively few studies have assessed the efficacy of benefit finding to mediate the relationship between illness perceptions and physical and psychosocial in other chronic disease studies (Helgeson et al., 2006; de Ridder et al., 2008). In one study that did conduct tests for mediation, Luszczynska et al. (2007) identified a role for benefit finding to mediate relations between self-efficacy (closely related to personal control) and physical adjustment among a

cohort of individuals living with the human immunodeficiency virus. Importantly, as reported in Study 1.1, benefit finding mediated the relationships between personal control and life satisfaction, and between personal control and positive affect. These results support the inclusion of psychological interventions that seek to strengthen personal control perceptions or more internally focussed locus of control beliefs along with benefit finding ability or assisting individuals to discovery positive meaning in relation to their HCV, with the aim of improving quality of life outcomes.

Including benefit finding within the SRM reported in Study 1.1 is an extension to the original SRM model which describes ongoing dynamic casual relationships between illness perceptions and health related outcomes, mediated by coping (Leventhal et al., 1980). A recommendation for future HCV research that utilises an expanded SRM would be to adopt longitudinal designs that would allow greater testing of the direction of causality in the relationships between illness perceptions, coping, benefit finding, and physical and psychosocial adjustment (Hagger & Orbell, 2003). Importantly, utilising longitudinal designs would also enhance the potential for the identification of roles for coping and benefit finding to mediate relations between illness perceptions and adjustment within the context of HCV in comparison to non-dynamic cross-sectional designs (Hagger & Orbell, 2003).

8.3 Relations Between Illness Perceptions, Coping, Benefit Finding, and HCV Treatment Response – Review of Longitudinal Studies.

Study 2.1 investigated whether baseline illness perceptions and coping strategies predicted HCV recovery after controlling for pre-treatment biomedical, clinical, behavioural and demographic variables. As reported in Study 2.1, only

treatment control, mental health comorbidity and use of recreational drugs demonstrated significant associations with HCV treatment response, and were therefore entered into subsequent logistic regression analysis. The results indicated that mental health comorbidity and increased use of recreational drugs predicted treatment response. It may be that the relatively counter-intuitive direction of the relationships of mental health comorbidity and the use of recreational drugs to treatment response, was due in part to the use of a dichotomous yes or no response format used to elicit information on these complex variables, that may not have provided a broad enough context to differentiate between specific mental health conditions, types of substance use and their potential contributions to the prediction of HCV treatment response. Future research in this area would do well to consider including specific mental health conditions and types of recreational drugs that have been identified as having high prevalence among individuals living with HCV (i.e., depression and intravenous drug use) (Chen & Morgan, 2006; Golden et al., 2006; Lee & Abdo, 2003; Shiffman et al., 2004). However, other research has identified a role for the use of recreational drugs to improve HCV treatment response rates (Costiniuk et al., 2008; Sylvestre et al., 2006). In contrast, another study did not find the same results (Liu et al., 2014). Interestingly, in relation to links between reported mental health comorbidity and HCV treatment response Sockalingham & Abbey (2009) reported early identification and treatment of depression in individuals presenting for HCV treatment predicted improved HCV treatment response outcomes.

Consistent with a related chronic disease study (Chilcot et al., 2011), after controlling for mental health comorbidity and recreational drug use, perceptions related to treatment control predicted HCV treatment response. The results

reported in the present thesis provide support for the inclusion of cognitive variables, such as illness perceptions, in future HCV treatment studies. Clinically, the identification of treatment control as a predictor of HCV treatment response opens the potential to improve biomedical treatment outcomes for individuals undertaking HCV treatment by altering maladaptive illness perceptions. In comparison to illness perception components, very few studies have investigated the ability of coping strategies to predict biomedical treatment outcomes (Hagger & Orbell, 2003). Therefore, the results for coping have a significantly lower existing evidence base across chronic disease studies in comparison to illness perceptions. This in turn limits the ability to conduct benchmarking analysis which may have helped to explain or account for the failure of coping strategies to predict HCV treatment response as reported in Study 2.1.

Study 2.2 investigated whether benefit finding could predict HCV treatment response after controlling for the clinical and behavioural variables over and above the contributions of treatment control. In Study 2.2 treatment control predicted HCV treatment response outcomes. Interestingly, after including benefit finding in the predictive model both the reporting of mental health comorbidity and the use of recreational drug use no longer made significant contributions to the model. In Study 2.2, lower benefit finding predicted HCV treatment response after accounting for the contributions of treatment control, mental health comorbidity and the use of recreational drugs. This relatively counter-intuitive result is consistent with the findings reported in Study 1.1, and with a number of other chronic disease studies that identified both intuitive and counter-intuitive results whilst investigating links between benefit finding, physical and psychosocial adjustment and biomedical treatment outcomes (de Ridder et al., 2008; Helgeson et

al., 2006; McMillen & Fisher, 1998). For example, as reported in Study 1.1, Tomich and Helgeson (2004) conducted a study among women who had recently been diagnosed with breast cancer. At 3-9 months follow up, benefit finding predicted higher depression. In a more expected direction, Bower et al., (1998) found that benefit finding predicted a more favourable immune status among individuals with human immunodeficiency virus at 2-3 year follow up and decreased mortality rates after 4-9 years.

Overall, results reported in the present thesis and across a number of other chronic health conditions have demonstrated a role for benefit finding in predicting biomedical outcomes, and accounting for variance in physical and psychosocial adjustment (de Ridder et al., 2008; Helgeson et al., 2006; McMillen & Fisher, 1998). Importantly, the present thesis is the first to demonstrate that benefit finding can predict HCV psychosocial adjustment and biomedical treatment outcomes within the context of an expanded SRM.

8.4 Review of Supplementary Longitudinal Study

Results of the longitudinal analysis reported in Study 2.3 identified the role of depression in predicting HCV treatment response after controlling for the use of recreational drugs. Lower reported depression predicted HCV treatment response. As outlined in Study 2.3, this result has important implications for clinical settings related to HCV, and provides support for the inclusion of comprehensive mood assessments for individuals presenting for HCV treatment. Contrary to expectations, physical health failed to predict HCV treatment response. As recommended in Study 2.3, future HCV studies may benefit from assessing individual physical health areas and their respective relations with HCV treatment response, rather than utilising the total scores of a number of physical health

related variables as used in the present thesis. Similarly, both life satisfaction and positive affect failed to predict HCV treatment response outcomes. Future HCV focussed research may benefit from utilising quality of life related variables that have demonstrated the efficacy to predict biomedical treatment outcomes in other areas of chronic disease.

8.5 Empirical Limitations

Firstly, future studies utilising the SRM within the context of HCV may benefit from adopting longitudinal designs to enable a more effective assessment of some of the dynamic aspects of the SRM (e.g., ongoing feed-back loop between features of the model) and help to limit the potential that cross-sectional designs have to generalise results of studies over time (Leventhal et al., 1997). Secondly, the sample size at Time 2 was relatively small compared to the baseline sample size at Time 1. One potential recommendation is to consider moving away from an anonymous online data collection design as used in the present study, and rather focus on clinic based, face to face approach that may potentially increase response rates, particularly at follow up data collection periods. Further, some of the methodological limitations (e.g., potential response bias) associated with the use of self-report yes/no response questions for measuring clinical, behavioural and demographic information may have contributed to the counter-intuitive findings regarding adherence, drug use and comorbidity. Future related studies could consider using standardised clinical measures for assessing medication adherence and other clinical markers such as substance use and mental health as a way of potentially avoiding some of the more counter-intuitive results reported in the present thesis.

A relatively large number of regression analyses were performed in the present thesis. Future related studies that conduct a similar number of regression tests may consider setting a more stringent p value to control for potential Type 1 errors, then the $p < .05$ value that was utilised in regression tests reported in the present thesis. However, due in part to the relatively challenging process of recruiting study participants among HCV sufferers, it was intentionally decided not to control for potential Type 1 errors in regression analyses reported in the present thesis. This strategy which has support from a theoretical perspective (Tabachnik & Fidell, 2001), particularly when as in the present thesis ranges of scores were regressed against each other, allowed all potentially meaningful relationships between variables to be revealed. Finally, Sobel tests for mediation were utilised in the present thesis (Baron & Kenny, 1986). This traditional method for testing for mediation between variables has strong theoretical support in the literature providing the primary rationale for including this approach in the present thesis (Baron & Kenny, 1986). However, future studies may benefit from considering more recent mediation approaches, such as bootstrapping to compliment the use of Sobel tests when conducting mediation analyses, particularly if investigators are seeking to increase the power of the study which can at the same time reduce the potential for Type II errors (Baron & Kenny, 1986; Preacher & Hayes, 2004). Further, bootstrapping also does not rely as heavily as the Sobel method for assumptions of normality to be met (Preacher & Hayes, 2004). However, the bootstrapping method can be more vulnerable in comparison to the Sobel method to the presence of outliers in the data which can increase the potential for Type 1 errors to occur particularly when there is a relatively small participant sample as was reported in the present thesis (Preacher & Hayes, 2004).

8.6 Conclusion and Future Directions

A number of studies have demonstrated the efficacy of illness perceptions, coping and benefit finding to account for variance in physical and psychosocial adjustment and bio-medical treatment outcomes across a range of diverse chronic health conditions (Broadbent et al., 2015; de Ridder et al., 2008; Hagger & Orbell, 2003; Helgeson et al., 2006; McMillen & Fisher, 1998). The present thesis produced results consistent with previous work within the novel area of HCV. The data reported here demonstrated that key individual and combined features of an expanded SRM (refer Appendix A), including illness perceptions, coping and benefit finding, could predict physical and psychosocial adjustment and treatment response among individuals with HCV. Additionally, both coping and benefit finding demonstrated efficacy in mediating some of the relationships between illness perceptions and physical and psychosocial adjustment, and lower depression predicted HCV treatment response. Finally, important to clinical practice, and consistent with other areas of chronic disease (Chilcot & Moss-Morris, 2013; de Ridder et al., 2008; McMillen & Fisher, 1998), results reported in the present thesis support providing psychological interventions that target maladaptive illness perceptions and coping strategies along with providing opportunities for individuals to discover illness related benefits or positive meaning, and for conducting comprehensive mood assessments for individuals presenting for HCV treatment.

References

- Adler, N., & Matthews, K. (1994). Health psychology: Why do some people get sick and some stay well? *Annual Review of Psychology*, 38, 221-251.
- Affleck, G., Tennen, H., Croog, S., & Levine, S. (1987). Causal attribution, perceived benefits, and morbidity after a heart attack: an 8-year study. *Journal of Clinical and Consulting Psychology*, 55, 29-35.
doi.org/10.1037/0022-006X.55.1.29.
- Ajzen, I. (1991). The theory of planned behaviour. *Organizational behaviour and human decision processes*, 50, 179-211.
- Alter, M. J. (1997). The epidemiology of acute and chronic hepatitis C. *Clinics in Liver Disease*, 1, 559-568.
- Algoe, S. B., & Stanton, A. L. (2009). Is benefit finding good for individuals with chronic disease? In C. L. Park, S. C. Lechner, M. H. Antoni, & A. L. Stanton (Eds.), *Medical Illness and positive life change: can crisis lead to personal transformation?* (pp. 173-194). Washington: APA.
- Antoni, M. H., Lehman, J. M., Klibourn, K. M., Boyers, A. E., Culver, J. L., Alfrei, S. M., ...Carver, C. S. (2001). Cognitive-behavioural stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychology*, 20, 20-32.
- Australian National Council on AIDS, Hepatitis C and Related Diseases, Hepatitis C Sub-Committee. (2002). *Hepatitis C virus projections working group: estimates and projections of the hepatitis C virus epidemic in Australia*. Sydney, Australia: NCHECR.

- Bacon, B. R., Farahvash, M. J., Janney, C. G., & Neuschwander-Tetri, B. A. (1994). Nonalcoholic steatohepatitis: An expanded clinical entity. *Gastroenterology*, 107, 1103-1109.
- Barkhuizen, A., Rosen, H. R., Wolf, S., Flora, K., Benner, K., & Bennett, R. M. (1999). Musculoskeletal pain and fatigue are associated with chronic hepatitis C: A report of 239 hepatology clinic patients. *The American Journal of Gastroenterology*, 94, 1355-1360. doi: 10.1111/j.1572-0241.1999.01087
- Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. *Journal of Personality and Social Psychology*, 51, 1173-1182.
- Batey, R., G.(2002). Hepatitis C: Where are we at and where are we going? *The Medical Journal of Australia*, 176, 361-362.
- Bayard, M., Holt, J., & Boroughs, E. (2006). Nonalcoholic fatty liver disease. *American Family Physician*, 73, 1961-1968.
- Bellizzi, K. M., & Blank, T. O. (2006). Predicting posttraumatic growth in breast cancer survivors. *Health Psychology*, 25, 47-56.
- Benvegna, L., Gios, M., Boccato, S., & Alberti, A. (2004). Natural history of compensated viral cirrhosis: A prospective study on the incidence and hierarchy of major complications. *Gut*, 53, 744-749. doi: 10.1136/gut.2003.020263
- Bianchi, G., Loguercio, C., Sgarbi, D., Abbiati, R., Chen, C. H., Di Pierro, M., ... Marchesini, G. (2000). Reduced quality of life in patients with Hepatitis C:

Effects of interferon treatment. *Digestive and Liver Disease*, 32, 398-405.

doi:10.1016/S1590-8658(00)80260-1

Boddington, E., Myers, L. B., & Newman, S. P. (2002). Illness severity, illness perceptions and health related quality of life in patients with Irritable Bowel Syndrome. Paper presented at the British Psychological Society Division of Health Psychology annual conference 2002, Sheffield, England.

Bonkovsky, H. L., Snow, K. K., Malet, P. F., Back-Madruga, C., Fontana, R. J., Sterling, R. K., ... Gretch, D. R. (2007). Health-related quality of life in patients with chronic hepatitis C and advanced fibrosis. *Journal of Hepatology*, 46, 420-431.

Bower, J. E., Kemeny, M. E., Taylor, S. E., & Fahey, J. L. (1998). Cognitive processing, discovery of meaning, CD4 decline, and AIDS-related mortality among bereaved HIV-seropositive men. *Journal of Consulting and Clinical Psychology*, 66, 979 – 986.

Bower, J. E., Meyerowitz, B. E., Desmond, K. A., Bernaards, C. A., Rowland, J. H., & Ganz, P. A. (2005). Perceptions of positive meaning and vulnerability following breast cancer: Predictors and outcomes among long-term breast cancer survivors. *Annals of Behavioral Medicine*, 29, 236-245. DOI: 10.1207/s15324796abm2903_10.

Bradburn, N. M. (1969). *The Structure of Psychological Well-Being*. Aldine: Chicago.

Brazier, J. E., Harper, R., Jones, N. M., O’Cathain, A., Thomas, K. J., Usherwood, T., & Westlake L., (1992). Validating the SF-36 health survey

- questionnaire: New outcome measure for primary care. *British Medical Journal*, 305, 160-164.
- Broadbent, E. (2010). Illness perceptions and health: Innovations and clinical applications. *Social Personality Psychology Compass*, 4, 256-266.
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of Psychosomatic Research*, 60, 631-637. doi:10.1016/j.jpsychores.2005.10.020
- Broadbent, E., Kydd, R., Sanders, D., & Vanderpyl, J. (2008). Unmet needs and treatment seeking in high users of mental health services: Role of illness perceptions. *Australian and New Zealand Journal of Psychiatry*, 42, 147-153. doi:10.1080/00048670701787503
- Broadbent, E., Wilkes, C., Koschwanez, H., Weinman, J., Norton, S., & Petrie, K. J. (2015). A systematic review and meta-analysis of the Brief Illness Perception Questionnaire. *Psychology & Health*, 30, 1361-1385. doi: 10.1080/08870446.2015.1070851
- Brener, L., von Hippel, W., & Kippax, S. (2007). Prejudice among health care workers toward injecting drug users with hepatitis C: Does greater contact lead to less prejudice? *International Journal of Drug Policy*, 18, 381-387. doi:10.1016/j.drugpo.2007.01.006
- Buick, D. L. (1998). Illness representations and breast cancer: Coping with radiation and chemotherapy. In K. J. Petrie & J. A. Weinman (Eds.), *Perceptions of health and illness: Current research and applications*. (pp. 379 – 410). Australia: Harwood Academic.

- Butler, J., & Quinn, C. (2003). *Evaluation of the commonwealth funded hepatitis C education and prevention program, 1999-2000 to 2002-2003*. A report prepared for the commonwealth department of health and ageing, Canberra, Australia.
- Butt, G. (2008). Stigma in the context of hepatitis C: Concept analysis. *Journal of Advanced Nursing*, 62, 712-724.
- Callegari, A., Michelini, I., Sguazzin, C., Catona, A., & Klersy, C. (2005). Efficacy of the SF-36 questionnaire in identifying obese patients with psychological discomfort. *Obesity Surgery*, 15, 254-260.
- Caltabiano, M. L., & Ricciardelli, L. A. (2013). *Applied topics in health psychology*. West Sussex, UK: John Wiley & Sons.
- Cameron, L. D., & Leventhal, H. (2003). Self-regulation, health, and illness. An overview. In L. D. Cameron, & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 1-13). New York: Routledge.
- Canary, L. A., Kleven, R. M., & Holmberg, S. D. (2015). Limited access to new hepatitis C virus treatment under state Medicaid programs. *Annals of Internal Medicine*, 3, 226-228.
- Cartwright, T., & Lamb, R. (1999). *The self-regulatory model: a framework for chronic illness*. Paper presented at the British Psychological Society Division of Health Psychology Annual Conference 1999, Leeds, England.
- Carver, C. S., & Scheier, M. F. (1983). A control-theory model of normal behaviour, and implications for problems in self-management. In P. C. Kendall (Ed.), *Advances in cognitive-behavioural research and therapy* (pp. 127-194). New York: Academic Press.

- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically-based approach. *Journal of Personality and Social Psychology*, 56, 267-283.
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief COPE. *International Journal of Behavioural Medicine*, 4, 92-100.
- Carver, C. S., & Antoni, M. H. (2004). Finding benefit in breast cancer during the year after diagnosis predicts better adjustment 5 to 8 years after diagnosis. *Health Psychology*, 23, 595 – 598. DOI: 10.1037/0278-6133.23.6.595.
- Carver, C. S., Lechner, S. C., & Antoni, M. H. (2004). Challenges in studying positive change after adversity: Illustrations from research on breast cancer. In C. L. Park, S. C. Lechner, M. H. Antoni, & A. L. Stanton (Eds.), *Medical illness and positive life change: Can crisis lead to personal transformation?* (pp. 51-62). Washington: APA.
- Chapko, M. K., Sloan, K. L., Davison, J. W., DuFour, D. R., Bankson, D. D., Rigsby, M. L., & Dominitz, J. A. (2005). Cost effectiveness of testing strategies for chronic Hepatitis C. *The American Journal of Gastroenterology*, 100, 607-615. doi: 10.1111/j.1572-0241.2005.40531
- Chen, S. L., & Morgan, T. R. (2006). The natural history of hepatitis C virus (HCV) infection. *International Journal of Medical Science*, 3, 47-52.
- Cheng, S. J., Bonis, P. L., Lau, J., Pham, N. Q., & Wong, J. B. (2001). Interferon and ribavirin for patients with chronic hepatitis C who did not respond to previous interferon therapy: A meta-analysis of controlled and uncontrolled trials. *Hepatology*, 33, 231-240.

- Chilcot, J., Wellsted, D., & Farrington, K. (2011). Illness perceptions predict survival in haemodialysis patients. *American Journal of Nephrology*, 33, 358-368. Doi: 10.1159/000326752.
- Chilcot, J., & Moss-Morris, R. (2013). Changes in illness related cognitions rather than distress mediate improvements in irritable bowel syndrome (IBS) symptoms and disability following a brief cognitive behavioural therapy intervention. *Behaviour Research and Therapy*, 51, 690-695.
- Choo, Q. L., Kuo, G., Weiner, A. J., Overby, L. R., Bradley, D. W., & Houghton, M. (1989). Isolation of a cDNA clone derived from a blood-borne non-A, non-B viral hepatitis genome. *Science*, 244, 359-62.
- Clara, I. P., Cox, B. J., & Enns, M. W. (2001). Confirmatory factor analysis of the Depression Anxiety Stress scales in depressed and anxious patients. *Journal of Psychopathology and Behavioural Assessment*, 23, 61-67.
- Cooper, C., Katona, C., & Livingston, G. (2008). Validity and reliability of the Brief Cope in carers of people with dementia. The Laser-AD study. *The Journal of Nervous Disease*, 196, 838-843.
- Coppola, A. G., Karakousis, P. C., Metz, D. C., Go, M. F., Mhokashi, M., Howden, C. W.,... Sharma, V. K. (2004). Hepatitis C knowledge among primary care residents: Is our teaching adequate for the times? *The American Journal of Gastroenterology*, 99, 1720-1725. doi: 10.1111/j.1572-0241.2004.10370
- Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001). Posttraumatic growth following breast cancer: A controlled comparison study. *Health Psychology*, 20, 176-185.

- Costiniuk, C. T., Mills, E., & Cooper, C. L. (2008). Evaluation of oral cannabinoid-containing medications for the management of interferon and ribavirin-induced anorexia, nausea and weight loss in patients treated for chronic hepatitis C virus. *Canadian Journal of Gastroenterology*, 22(4), 376–380.
- Covic, T., Cumming, S. R., Pallant, J. F., Manolios, N., Emery, P., Conaghan, P. G., & Tennant, A. (2012). Depression and anxiety in patients with rheumatoid arthritis: prevalence rates based on a comparison of the Depression, Anxiety and Stress Scale (DASS) and the hospital, Anxiety and Depression Scale (HADS). *BMC Psychiatry* 12:6, 1-10. doi: 10.1186/1471-244X-12-6
- Crofts, N. (2001). Going where the epidemic is. Epidemiology and control of Hepatitis C among injecting drug users. *Australian Family Physician*, 30, 420-425.
- Crofts, N., Aitken, C., & Kaldor, J. (1999). The force of numbers: Why hepatitis C is spreading among Australian injecting drug users while HIV is not. *The Medical Journal of Australia*, 170, 220-221.
- Covic, A., Seica, A., Gusbeth-Tatomir, P., Gavrilovici, O., & Goldsmith, D. J. A. (2004). Illness representations and quality of life scores in haemodialysis patients. *Nephrology Dialysis Transplantation*, 19, 2078-2083.
- Daleboudt, G., Broadbent, E., McQueen, F., & Kaptein, A. A. (2013). The impact of illness perceptions on sexual functioning in patients with systemic lupus erythematosus. *Journal of Psychosomatic Research*, 74, 260–264. doi: 10.1016/j.psychores.2012.11.004

- Danoff-Burg, S., & Revenson, T. A. (2005). Benefit-finding among patients with rheumatoid arthritis: positive effects on interpersonal relationships. *Journal of Behavioral Medicine*, 28, 91 – 103.
- Davis, G. L. (2002). Monitoring of viral levels during therapy of hepatitis C. *Hepatology*, 36, 145-151.
- De Gucht, V. (2015). Illness perceptions mediate the relationship between bowel symptom severity and health-related quality of life in IBS patients. *Quality of Life Research*, 24, 1845-1856. Doi: 10.1007/s11136-015-0932-8.
- Department of Health and Ageing. (2005). *National hepatitis C strategy 2005-2008*. Canberra, Australia.
- de Ridder, D., Depla, M., Severens, P., & Malsh, M. (1997). Beliefs on coping with illness: A consumers perspective. *Social Science and Medicine*, 44, 553-559. doi:10.1016/S0277-9536(96)00085-8.
- De Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *Lancet*, 372, 246 – 255.
- Diefenbach, M. A., & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress and the Homeless*, 5, 11-38. doi: 10.1007/BF02090456
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, 49, 71-75.
- Dubernard, G., Rouzier, R., David-Montefiore, E., Bazot, M., & Darai, E. (2008). Use of the SF-36 questionnaire to predict quality-of-life improvement after laparoscopic colorectal resection for endometriosis. *Human Reproduction*, 23, 846-851.

Dusheiko, G. M. (1996). Summary: Antiviral treatment of hepatitis C virus.

Antiviral Research, 29, 77-82.

Economic Evaluation of Hepatitis C in Australia. (2005). *Report Prepared for the*

Australian government department of health and ageing. Sydney,

Australia: Applied Economics Pty Ltd.

Edlin, B. R. (2002). Prevention and Treatment of Hepatitis C in Injection Drug

Users. *Hepatology (Baltimore, Md.)*, 36(5 Suppl 1), S210–S219.

<http://doi.org/10.1053/jhep.2002.36809>

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible

statistical power analysis program for the social, behavioral, and

biomedical sciences. *Behavior Research Methods*, 39, 175-191.

Felton, B. J., & Revenson, T. A. (1987). Age differences in coping with chronic

illness. *Psychology and Aging*, 2, 164-170.

Fitzell, A., & Pakenham, K. I. (2010). Application of a stress and coping model to

positive and negative adjustment outcomes in colorectal cancer caregiving.

Psycho-Oncology, 19, 1171-1178. Doi: 10.1002/pon.1666.

Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged

community sample. *Journal of health and Social Behaviour*, 21, 219-239.

Folkman, S., & Lazarus, R. S. (1988). Coping as a mediator of emotion. *Journal of*

Personality and Social Psychology, 54, 466-475.

Fowler, C. L. (2007). *Illness representations, coping, and quality of life in patients*

with Hepatitis C undergoing antiviral therapy (Doctoral dissertation).

University of Cincinnati, Cincinnati, OH.

- Forton, D. M., Taylor-Robinson, S. D., & Thomas, H. C. (2003). Cerebral dysfunction in chronic hepatitis C infection. *Journal of Viral Hepatitis*, 10, 81-86. doi: 10.1046/j.1365-2893.2003.00416
- Fortune, D. G., Richards, H. L., Griffiths, C. E. M., & Main, C. J. (2002). Psychological stress, distress and disability in patients with psoriasis: Consensus and variation in the contribution of illness perceptions, coping and alexithymia. *British Journal of Clinical Psychology*, 41, 157-174. doi: 10.1348/014466502163949
- Fortune, D. G., Richards, H. L., Griffiths, C. E. M., & Main, C. J. (2005). Adversarial growth in patients undergoing treatment for psoriasis: A prospective study of the ability of patients to construe benefits from negative events. *Psychology, Health & Medicine*, 10, 44-56. doi: 10.1080/13548500512331315352.
- Foster, G. R., (2010). Pegylated interferons for the treatment of chronic hepatitis C: pharmacological and clinical differences between peginterferon-alpha-2a and peginterferon-alpha-2b. *Drugs*, 70, 147-165.
- Fried, M. W., Shiffman, M. L., Reddy, K. R., Smith, C., Marinos, G., Goncales, F. L.,... Yu, J. (2002). Peginterferon alfa-2a plus ribavirin for chronic hepatitis C virus infection. *New England Journal of Medicine*, 347, 975-982. Retrieved from <http://www.nejm.org/doi/full/10.1056/NEJMoa020047>
- Friedman, S. L. (1999). Hepatic fibrosis. In E. R. Schiff, M. F. Sorrell, & W. C. Maddrey (Eds.), *Diseases of the liver* (8th ed, pp. 371-385). Philadelphia, Pa: Lippincott-Raven.

- Frostholt, L., Oernboel, E., Christensen, K. S., Toft, T., Olesen, F., Weinman, J., & Fink, P. (2007). Do illness perceptions predict health related outcomes in primary care patients? A 2-year follow-up study. *Journal of Psychosomatic Research*, 62, 129-138.
doi:10.1016/j.jpsychores.2006.09.003
- Fusar-Poli, P., Klersy, C., Stramesi, F., Callegari, A., Arbustini, E., & Politi, P. (2008). Determinants of quality of life in marfan syndrome. *Psychosomatics*, 49, 243-248.
- Gane, E., Stedman, C., Brunton, C., Radke, S., Henderson, C., Estes, C., & Razavi, H. (2014). Impact of Improved treatment on disease burden of chronic hepatitis C in New Zealand. *New Zealand Medical Journal*, 127, 61-74.
- Gibbons, A., Groarke, A., & Sweeney, K. (2016). Predicting general and cancer-related distress in women with newly diagnosed breast cancer. *BMC Cancer*, 16, 935. <http://doi.org/10.1186/s12885-016-2964-z>.
- Glacken, M., Coates, V., Kernohan, G., & Hegarty, J. (2003). The experience of fatigue for people living with hepatitis C. *Journal of Clinical Nursing*, 12, 244-252. doi: 10.1046/j.1365-2702.2003.00709
- Golden, J., Conroy, R. M., O'Dwyer, A. M., Golden, D., & Hardouin, J-B. (2006). Illness-related stigma, mood and adjustment to illness in persons with hepatitis C. *Social Science and Medicine*, 63, 3188-3198.
- Goodman, D., Morrissey, S., Graham, D., & Bossingham, D. (2005). The application of cognitive-behaviour therapy in altering illness representations of systemic lupus erythematosus. *Behaviour Change*, 22, 156-171.

- Greco, A., Steca, P., Pozzi, R., Monzani, D., D'Addario, M., Villani, A., ...Parati, G. (2014). Predicting depression from illness severity in cardiovascular disease patients: Self-efficacy beliefs, illness perception, and perceived social support as mediators. *International Journal of Behavioral Medicine*, 21, 221-229. doi: 10.1007/s12529-013-9290-5
- Greenberger, P. (1998). Hidden risk of Hepatitis C. *Journal of Womens Health*, 7, 797-798.
- Griva, K., Myers, L. B., & Newman, S. (2000). Illness perceptions and self efficacy beliefs in adolescents and young adults with insulin dependent diabetes mellitus. *Psychology and Health*, 15, 733-750.
- Gross, J. B., Therneau, T. M., Johnson, S. M., Kwo, P. Y., Afdhal, N. H., & Flamm, S. L. (2003). The RENEW trial: A national, multicenter study of high-dose peginterferon alfa-2b + ribavirin for non-responders with hepatitis C. *Hepatology*, 38, A312.
- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health*, 18, 141-184.
- Retrieved from
<http://www.essex.ac.uk/psychology/psy/people/orbell/HaggerOrbell2003.pdf>
- Hagger, M. S., & Orbell, S. (2005). A confirmatory factor analysis of the revised illness perception questionnaire (IPQ-R) in a cervical screening context. *Psychology and Health*, 20, 161-173.
- Hallinan, R., Byrne, A., Kingsley, A., & Dore, G. J. (2007). Referral for chronic hepatitis C treatment from a drug dependency treatment setting. *Drug and Alcohol Dependence*, 88, 49-53. doi:10.1016/j.drugalcdep.2006.09.018

- Hampson, S. E., Glasgow, R. E., & Toobert, D. J. (1990). Personal models of diabetes and their relations to self-care activities. *Health Psychology, 9*, 632-646
- Hanafiah, K. M., Groeger, J., Flaxman, A. D., & Wiersma, S. T. (2013). Global epidemiology of hepatitis C infection: New estimates of age-specific antibody to HCV seroprevalence. *Hepatology, 57*, 1333 – 1342.
- Hassanein, T., Cooksley, G., Sulkowski, M., Smith, C., Marinos, G., Lai, M. Y.,...Green, J. (2004). The impact of peginterferon alfa-2a plus ribavirin combination therapy on health-related quality of life in chronic hepatitis C. *Journal of Hepatology, 40*, 675-681.
- Hauser, W., Zimmer, C., Schiedermaier, P., & Grandt, D. (2004). Biopsychosocial predictors of health related quality of life in patients with chronic hepatitis C. *Psychosomatic Medicine, 66*, 954-958.
doi:10.1097/01.psy.0000145824.82125.a8
- Heckman, T. (2003). The chronic illness quality of life (CIQOL) model: Explaining life satisfaction in people living with HIV disease. *Health Psychology, 22*, 140-147.
- Heijmans, M. J. W. M. (1998). Coping and adaptive outcome in chronic fatigue syndrome: Importance of illness cognitions. *Journal of Psychosomatic Research, 45*, 39-51.
- Heijmans, M. (1999). The role of patients illness representations in coping and functioning with Addison's disease. *British Journal of Health Psychology, 4*, 137-149. doi: 10.1348/135910799168533
- Heintges, T., & Wands, J. (1997). Hepatitis C virus: epidemiology and transmission. *Hepatology, 25*, 521-526. doi: 10.1002/hep.510260338

- Helder, D. I., Kaptein, A. A., van Kempen, G. M. J., Weinman, J., van Houwelingen, H. C., & Roos, R. A. C. (2002). Living with Huntingtons disease: Illness perceptions, coping mechanisms, and patients well-being. *British Journal of Health Psychology*, 7, 449-462.
doi: 10.1348/135910702320645417
- Helgeson, V. S., Reynolds, K. A., & Tomich, P. L. (2006). A meta-analytic review of benefit finding and growth. *Journal of Consulting and Clinical Psychology*, 74, 797-816
- Henry, J. D., & Crawford, J. R. (2005). The short form version of the Depression Anxiety Stress scales (DASS-21): Construct validity and normative data in a large non-clinical sample. *British Journal of Clinical Psychology*, 44, 227-239.
- Hepatitis C in Australia*. (2007). Retrieved June 26th, 2010, from the Hepatitis Australia web site:
http://www.hepatitisaustralia.com/documents/factsheet_media.pdf
- Hepatitis C Virus Projections Working Group. (2002). *Estimates and Projections of Hepatitis C Virus Epidemic in Australia*. Sydney, NSW: National Centre in HIV Epidemiology and Clinical Research.
- Hepatitis C Virus Projections Working Group (2006) *Estimates and Projections of the Hepatitis C Virus Epidemic in Australia*. Sydney, NSW: National Centre in HIV Epidemiology and Clinical Research.
- Hepatitis C Retreatment Approved!* (2008). Retrieved June 30th, 2010, from the Hepatitis Council web site: <http://hepqld.asn.au/content/view/135/98>
- Ho, S. B., Nguyen, H., Tetrack, L. L., Opitz, G. A., Basara, M. L., & Dieperink, E. (2001). Influence of psychiatric diagnoses on interferon-alpha treatment for

- chronic hepatitis C in a veteran population. *The American Journal of Gastroenterology*, 96, 157-164. doi: 10.1111/j.1572-0241.2001.03468
- Holahan, C. J., & Moos, R. H. (1987). Personal and contextual determinants of coping strategies. *Journal of Personality and Social Psychology*, 52, 946-955.
- Holmes, J., Thompson, A., & Bell, S. (2013). Hepatitis C: An update. *Australian Family Physician*, 47, 452-456.
- Hollander, A., Foster, G. R., & Weiland, O. (2006). Health-related quality of life before, during and after combination therapy with interferon and ribavirin in unselected Swedish patients with chronic hepatitis C. *Scandinavian Journal of Gastroenterology*, 41, 577-585.
- Hoofnagle, J. H. (1997). Hepatitis C: The clinical spectrum of disease. *Hepatology*, 26, 15-20.
- Horne, R., Cooper, V., Fisher, M., Buick, D., & Weinman, J. (2001). Predicting acceptance of highly active retroviral treatment (HAART): the utility of an extended self-regulatory model. Paper presented at the European Health Psychology Society/BPS Annual Conference, St Andrews, Scotland, September 5-8.
- Horne, R., & Weinman, J. (2002). Self-regulation and self-management in asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychology and Health*, 17, 17-32.
- Iosue, K. (2002). Chronic hepatitis C: Latest treatment options. *The Nurse Practitioner*, 27, 32-49.
- Jacobson, I., Ahmed, F., Russo, M. W., Brown, R. S., Lebovics, E., Min, A.,...Brass, C. (2003). Pegylated interferon alfa-2b plus ribavirin in

patients with chronic hepatitis C: A trial in prior nonresponders to interferon monotherapy or combination therapy and in combination therapy relapsers: Final results. *Gastroenterology*, 124, A714. doi:10.1016/S0016-5085(03)83604-1

Jacobson, I. M., Pawlotsky, J. M., Afdhal, N. H., Dusheiko, G. M., Forns, X., Jensen., ... Schulz, J. (2012). A practical guide for the use of boceprevir and telaprevir for the treatment of hepatitis C. *Journal of Viral Hepatitis*, 19, 1-26. doi:10.1111/j.1365-2893.2012.01590.x

Janoff-Bulman, R. (1992). *Shattered assumptions: towards a new psychology of trauma*. NY: Free-Press.

Joshi, S, Dhungana, R. R., & Subba, U. K. (2015). Illness perceptions and depressive symptoms among persons with type 2 diabetes mellitus: An analytical cross-sectional study in clinical settings in Nepal. *Journal of Diabetes Research*, vol. 2015, 9 pages. doi:10.1155/2015/908374

Kaiser, S., Hass, H., & Gregor, M. (2004). Successful retreatment of chronic hepatitis C patients with a nonresponse to standard interferon and ribavirin using daily consensus interferon and ribavirin. *Hepatology*, 40, A241.

Kemp, S., Morley, S., & Anderson, E. (1999). Coping with epilepsy: Do illness representations play a role? *British Journal of Clinical Psychology*, 38, 43-58.

Koff, R. S. (2000). Outcomes and cost of care in Hepatitis C: Combination therapy scores again. *The American Journal of Gastroenterology*, 95, 1392-1393. doi: 10.1016/S0002-9270(00)00859-5

- Koziel, M. J. (2005). Cellular immune responses against Hepatitis C virus. *Clinical Infectious Diseases*, 41, 25-31. doi: 10.1086/429492
- Kyngas, H., Mikkonen, R., Nousiainen, E-M., Ryttilähti, M., Seppanen, P.,
Vaattovaara, R., & Jamsa, T. (2000). Coping with onset of cancer: Coping strategies and resources of young people with cancer. *European Journal of Cancer Care*, 10, 6-11.
- Lau, R. R., & Hartman, K. A. (1983). Common sense representations of common illness. *Health Psychology*, 2, 167-185.
- Law, M. G., & Batey, R. (2003). Injecting drug use in Australia: Needle/syringe programs prove their worth, but hepatitis C still on the increase. *The Medical Journal of Australia*, 178, 197-198.
- Law, M. G., Dore, G. J., Bath, N., Thompson, S., Crofts., Dolan, K.,...Wodak, A. (2001). Modelling hepatitis C virus incidence, prevalence and long-term sequelae in Australia. *International Journal of Epidemiology*, 32, 717-724. doi: 10.1093/ije/dyg101
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.
- Lazarus, R. S., & Folkman, S. (1987). Transactional theory and research of emotions and coping. *European Journal of Personality*, 1, 141-169.
- Lechner, S. C., Carver, C. S., Antoni, M. H., Weaver, K. E., & Phillips, K. M. (2006). Curvilinear associations between benefit finding and psychosocial adjustment to breast cancer. *Journal of Consulting and Clinical Psychology*, 74, 828-840.
- Lechner, S. C., Zakowski, S. G., Antoni, M. H., Greehawt, M., Block, K., & Block, P. (2003). Do sociodemographic and disease-related variables

influence benefit-finding in cancer patients? *Psycho-Oncology*, 12, 491-499.

Lee, S. S., & Abdo, A. A. (2003). Predicting antiviral treatment response in chronic hepatitis C: how accurate and how soon? *Journal of Antimicrobial Chemotherapy* 51, 487-491. doi: 10.1093/jac/dkg135

Lee, C. Y., & Harrison, S. A. (2005). Antiviral therapy for the management of Hepatitis C. *Hospital Physician*, 41, 31-36.

Lee, B., Chaboyer, W., & Wallis, M. (2008). Predictors of health related quality of life 3 months after traumatic injury. *Journal of Nursing Scholarship*, 40, 83-90. doi: 10.1111/j.1547-5069.2008.00210

Lehman, C. L., & Cheung, R. C. (2002). Depression, anxiety, post-traumatic stress, and alcohol related problems among veterans with chronic hepatitis C. *The American Journal of Gastroenterology*, 97, 2640-2646. doi: 10.1016/S0002-9270(02)04400-3

Leventhal, H., Diefenbach, M., & Leventhal, E. A. (1992). Illness cognition: Using common sense to understand treatment adherence and affect cognition treatment. *Cognitive Therapy and Research*, 16, 143-163. doi: 10.1007/BF01173486

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense model of illness danger. In Rachman, S. (Ed.), *Medical Psychology*, pp. 7-30. New York: Pergamon.

Levy, M., Baum, F., & Thomas, H. (2002). *Review of national hepatitis C strategy 1999-2000 to 2003-2004; the road not taken*. Canberra, Australia: Department of Health and Ageing.

- Lieber, C. (2001). Alcohol and hepatitis C. *Alcohol Research and Health*, 25, 245-254.
- Lin, O. S., & Keefe, E. B. (2001). Current treatment strategies for chronic hepatitis B and C. *Annual Review of Medicine*, 52, 29-49.
- Linley, P. A., & Joseph, S. (2004). Positive change following trauma and adversity: A review. *Journal of Traumatic Stress*, 17, 11-21.
- Littlewood, R. A., Vanable, P. A., Carey, M. P., & Blair, D. C. (2008). The association of benefit finding to psychosocial and health behaviour adaptation among HIV+ men and women. *Journal of Behavioral Medicine*, 31, 145-155. doi: 10.1007/s10865-007-9142-3.
- Liu, T., Howell, G. T., Turner, L., Corace, K., Garber, G., & Cooper, C. (2014). Marijuana use in hepatitis C infection does not affect liver biopsy histology or treatment outcomes. *Canadian Journal of Gastroenterology & Hepatology*, 28(7), 381–384.
- Lopes, A. A., Bragg, J., Young, E., Goodkin, D., Mapes, D., Combes, C.,... Port, F. K. (2002). Depression as a predictor of mortality and hospitalization among hemodialysis patients in the United States and Europe. *Kidney International*, 62, 199-207.
- Lovibond, S. H., & Lovibond, P. F. (1995). *Manual for the Depression Anxiety Stress Scales (DASS)*. Sydney: Psychology Foundation of Australia.
- Luhmann, N., Champagnat, J., Golovin, S., Maistat, L., Agustian, E., Inaridze, I., ... Bouscaillou, J. (2015). Access to hepatitis C treatment for people who inject drugs in low and middle income settings: Evidence from 5 countries in Eastern Europe and Asia. *International Journal of Drug Policy*, 26, 1081-1087. doi:10.1016/j.drugpo.2015.07.016

- Luszczynska, A., Sarkar, Y., & Knoll, N. (2007). Received social support, self-efficacy, and finding benefits in disease as predictors of physical functioning and adherence to antiretroviral therapy. *Patient Education and Counseling*, 66, 37-42. doi: 10.1016/j.pec.2006.10.002.
- Martinot-Peignoux, M., Boyera, N., Pouteau, M., Castelnau, C., Giuilys, N., Duchatelleb, V.,...Erlinger, S. (1998). Predictors of sustained response to alpha interferon therapy in chronic hepatitis C. *Journal of Hepatology*, 29, 214-223. doi:10.1016/S0168-8278(98)80006-8
- Mathew, A., Peiffer, L. P., Rhoades, K., & McGarrity, T. J. (2006). Improvement in quality of life measures in patients with refractory hepatitis C, responding to re-treatment with Pegylated interferon alpha -2b and ribavirin. *Health and Quality of Life Outcomes*, 12, 4:30.
- Meyer, D., Leventahl, H., & Gutman, M. (1985). Common-sense models of illness: The example of hypertension. *Health Psychology*, 4, 115-135.
- McGregor, B. A., Antoni, M. H., Boyers, A., Alferi, S. M., Blomberg, B. B., & Carver, C. S. (2004). Cognitive-behavioral stress management increases benefit finding and immune function among women with early-stage breast cancer. *Journal of Psychosomatic Research*, 56, 1-8. DOI:10.1016/S0022-3999(03)00036-9.
- McHutchison, J. G., Ware, J. E., Jr, Bayliss, M. S., Pianko S., Albrecht, J. K., Cort, S.,...Neary, M. P. (2001). The effects of interferon alpha-2b in combination with ribavirin on health related quality of life and work productivity. *Journal of Hepatology*, 34, 140-147. doi:10.1016/S0168-8278(00)00026

- McMillen, J. C., & Fisher, R. H. (1998). The perceived benefit scales: Measuring perceived positive life changes after negative events. *Social Work Research, 22*, 173-187. doi: 10.1093/swr/22.3.173.
- McMillen, J. C., & Cook, C. L. (2003). The positive by-products of spinal cord injury and their correlates. *Rehabilitation Psychology, 48*, 77-85.
- Mendez, P., Saeian, K, Reddy, K. R., Younossi, Z. M., Kerdel, F., Badalamenti, S.,...Schiff, E. R. (2001). Hepatitis C, cryoglobulinemia, and cutaneous vasculitis associated with unusual and serious manifestations. *The American Journal of Gastroenterology, 96*, 2489-2493. doi: 10.1016/S0002-9270(01)02622-3
- Miglioretti, M., Mazzini, L., Oggioni, G. D., Testa, L., & Monaco., F. (2008). Illness perceptions, mood and health related quality of life in patients with amyotrophic lateral sclerosis. *Journal of Psychosomatic Research, 65*, 603-609. doi:10.1016/j.jpsychores.2008.05.012
- Miller, R. L., Pallant, J. F., & Negri, L. M. (2006). Anxiety and stress in the postpartum: Is there more to postnatal distress than depression? *BMC Psychiatry, 6*, 1-11.
- Mohammed, S., Nagla, S., Morten, S., Asma, E., & Arja, A. (2015). Illness perceptions and quality of life among tuberculosis patients in Gezira, Sudan. *African Health Sciences, 15*(2), 385–393.
<http://doi.org/10.4314/ahs.v15i2.11>

- Moss-Morris, R., Petrie, K. J., & Weinman, J. (1996). Functioning in chronic fatigue syndrome: Do illness perceptions play a regulatory role? *British Journal of Health Psychology*, 1, 15-25.
- Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L. D., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and Health*, 17, 1-16.
- Moussalli, J., Opolon, P., & Poynard, T. (2002). Management of Hepatitis C. *Journal of Viral Hepatitis*, 5, 73-82. doi: 10.1046/j.1365-2893.1998.00086
- Nabi, H., Kivimaki, M., Vogli, R. De., Marmot, M. G., & Singh-Manoux, A. (2008). Positive and negative affect and risk of coronary heart disease: Whitehall II prospective cohort study. *BMJ*, 337, 32-36.
- National Centre in HIV Epidemiology and Clinical Research. (2004). *HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia*. Sydney, NSW: The University of New South Wales.
- National Centre in HIV Epidemiology and Clinical Research (2007). *HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia: Annual Surveillance Report 2007*. Sydney: Australian Institute of Health and Welfare
- National Centre in HIV Epidemiology and Clinical Research (2010). *Epidemiological and economic impact of potential increased hepatitis C treatment uptake in Australia*. Sydney, NSW: The University of New South Wales.

- Neri, S., Pulvirenti, D., & Bertino, G. (2006). Psychiatric symptoms induced by antiviral therapy in chronic hepatitis C: Comparison between interferon-alpha-2a and interferon-alpha-2b. *Clinical Drug Investigation*, 26, 655-662.
- Newell, M. L., & Pembrey, L. (2002). Mother to child transmission of hepatitis C virus infection. *Drugs of Today*, 38, 351-357. doi: 10.1358/dot.2002.38.5.668600
- Ngo-Metzger, Q., Sorkin, D. H., Mangione, C., Gandek, B., & Hays, R. D. (2008). Evaluating the SF-36 health survey (version 2) in older Vietnamese Americans. *Journal of Aging and Health*, 20, 420-436.
- Paddison, C. A. M., Alpass, F. M., & Stephens, C. V. (2008). Psychological factors account for variation in metabolic control and perceived quality of life among people with type 2 diabetes in New Zealand. *International Journal of Behavioral Medicine*, 15, 180-186.
- Pakenham, K. I. (2006). Investigation of the coping antecedents to positive outcomes and distress in Multiple Sclerosis (MS). *Psychology and Health*, 21, 633-649.
- Pakenham, K. I. (2007). The nature of benefit finding in multiple sclerosis (MS). *Psychology, Health & Medicine*, 12, 190-196. doi:10.1080/13548500500465878.
- Pakenham, K. I., & Cox, S. (2008). Development of the benefit finding in multiple sclerosis (MS) caregiving scale: A longitudinal study of relations between benefit finding and adjustment. *British Journal of Health Psychology*, 13, 583-682.

- Pakenham, K. I. (2011). Benefit finding and sense making in chronic illness. In S. Folkman (Ed.), *The Oxford handbook of stress, health and coping* (pp. 242-269). London: Oxford University Press.
- Pallant, J. (2007). *SPSS survival manual*. Sydney: Allen & Unwin.
- Park, C. L., Chmielewski, J., & Blank, T. O. (2009). Post-traumatic growth: finding positive meaning in cancer survivorship moderates the impact of intrusive thoughts on adjustment in younger adults. *Psycho-Oncology*, 19, 1139-1147.
- Paterson, B. L., Backmund, M., Hirsch, G., & Yim, C. (2007). The depiction of stigmatization in research about hepatitis C. *International Journal of Drug Policy*, 18, 364-373. doi:10.1016/j.drugpo.2007.02.004
- Pavot, W., & Diener, E. (1993). Review of the satisfaction with life scale, *Psychological Assessment*, 5, 164-172.
- Pawlotsky, J. M. (2003). Mechanisms of antiviral treatment efficacy and failure in chronic hepatitis C. *Antiviral Research*, 59, 1-11. doi:10.1016/S0166-3542(03)00088-3
- Perrillo, R., Rothstein, K. D., Rubin, R., Alam, L., Imperial J., Harb, G.,...Klaskala, W. (2004). Comparison of quality of life, work productivity and medical resource utilization of peginterferon alpha 2a vs the combination of interferon alpha 2b plus ribavirin as initial treatment in patients with chronic hepatitis C. *Journal of Viral Hepatitis*, 11, 157-165. doi: 10.1046/j.1365-2893.2003.00482
- Petriček, G., Vrcić-Keglević, M., Vuletić, G., Cerovečki, V., Ožvačić, Z., & Murgić, L. (2009). Illness Perception and Cardiovascular Risk Factors in

Patients with Type 2 Diabetes: Cross-sectional Questionnaire Study.

Croatian Medical Journal, 50(6), 583–593.

<http://doi.org/10.3325/cmj.2009.50.583>

Petrie, K. J., Cameron, L. D., Ellis, C. J., Buick, D., & Weinman, J. (2002).

Changing illness perceptions after myocardial infarction: An early intervention randomized controlled trial. *Psychosomatic Medicine*, 64, 580-586.

Petrie, K. J., Jago, L. A., & Devcich, D. A. (2007). The role of illness perceptions

in patients with medical conditions. *Current Opinion in Psychiatry*, 20, 163-167. doi: 10.1097/YCO.0b013e328014a871

Petrie, K. J., Weinman, J., Sharpe, N., & Buckley, J. (1996). Role of patients view

of their illness in predicting return to work and functioning after myocardial infarction: Longitudinal study. *British Medical Journal*, 312, 1191-1194.

Pierret, J. (2003). The illness experience: State of knowledge and perspectives for

research. *Sociology of Health & Illness*, 25, 4-22. doi: 10.1111/1467-9566.t01-1-00337

Pimm, T. J., & Weinman, J. (1998). Applying Leventhal's self-regulation model to

adaptation and intervention in rheumatic disease. *Clinical Psychology & Psychotherapy*, 5, 62-75. doi: 10.1002/(SICI)1099-0879(199806)

Platt, I., Green, H. J., Jayasinghe, R., & Morrissey, S. A. (2014). Understanding

adherence in patients with coronary heart disease: Illness representations and readiness to engage in healthy behaviours. *Australian Psychologist*, 49, 127-137. doi:10.1111/ap.12038

- Preacher, K. J., & Hayes, A. F. (2004). SPSS and SAS procedures for estimating indirect effects in simple mediation models. *Behavior Research Methods, Instruments, & Computers*, 36, 717-731.
- Radat, F., Lanteri-Minet, M., Nachit-Ouinekh, F., Massiou, H., Lucas, C., Pradalier, ..., El Hasnaoui, A. (2009). The GRIM2005 study of migraine consultation in France. III: Psychological features of subjects with migraine. *Cephalalgia*, 29, 338-350. doi: 10.1111/j.1468-2982.2008.01718
- Rahimi, J., Baljani, E., & Zadgasem, Z. (2012). Investigating the relationship between illness perception and quality of life in hemodialysis patients. *Iranian Journal of Critical Care Nursing*, 5, 151-158.
- Ramalho, F. (2003). Hepatitis C virus infection and liver steatosis. *Antiviral Research*, 60, 125-127.
- Rees, G., Fry, A., & Cull, A. (2001). A family history of breast cancer: women's experience from a theoretical perspective. *Social Science and Medicine*, 52, 1433-1440.
- Roesch, S. C., & Weiner, B. (2001). A meta-analytic review of coping with illness: Do causal attributions matter? *Journal of Psychosomatic Research*, 50, 205-219. doi:10.1016/S0022-3999(01)00188
- Rogan, C., Fortune, D. G., Prentice, G. (2013). Post-traumatic growth, illness perceptions and coping in people with acquired brain injury. *Neuropsychological Rehabilitation*, 23, 639-657. doi: 10.1080/09602011.2013.799076.
- Rosenstock, I. M. (1974). The health belief model and preventative health behaviour. *Health Education Monographs*, 2, 354-386.

- Rothenhausler, H. B., Scherr, M., Putz-Bankuti, C., Kapper, A., Stepan, A., Baranyi.,...Stauber, R. (2009). The relationship between emotional distress, cognitive performance and health – Related quality of life in patients with hepatitis C prior to anti-viral treatment. *Fortschritte der Neurologie, Psychiatrie*, 77, 457-463.
- Rutter, C. L., & Rutter, D. R. (2002). Illness representation, coping and outcome in irritable bowel syndrome (IBS). *British Journal of Health Psychology*, 7, 377-391.
- Sacks, S. L., Griffiths, P. D., Corey, L., Cohen, C., Cunningham, A., Dusheiko, G. M.,...Whitley, R. J. (2004). Lessons from HIV and hepatitis viruses. *Antiviral Research*, 63, 11-18.
- Sarkar, S., Sarkar, R., Berg, T., & Schaefer, M. (2015). Sadness and mild cognitive impairment as predictors for interferon-alpha-induced depression in patients with hepatitis C. *The British Journal of Psychiatry*, 206, 45-51.
doi: 10.1192/bjp.bp.113.141770
- Schaefer, M., Hinzpeter, A., Mohmand, A., Janssen, G., Pich, M., Schwaiger, M.,...Berg, T. (2007). Hepatitis C treatment in "difficult-to-treat" psychiatric patients with pegylated interferon-alpha and ribavirin: Response and psychiatric side effects. *Hepatology*, 46, 991-998.
doi: 10.1002/hep.21791
- Schaefer, M., & Mauss, S. (2008). Hepatitis C treatment in patients with drug addiction: Clinical management of interferon-alpha-associated psychiatric side effects. *Current Drug Abuse Reviews*, 1, 177-187.
- Scharloo, M., Kaptein, A., Weinman, J., Hazes, J. M., Willems, L. N. A., Bergaman., & Rooijmans, H. G. M. (1998). Illness perceptions, coping and

functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *Journal of Psychosomatic Research*, 44, 573-585. doi:10.1016/S0022-3999(97)00254-7

Scharloo, M., Kaptein, A. A., Weinman, J., Bergman, W., Vermeer, B. J., & Rooijmans, H. G. M. (2000). Patients illness perceptions and coping as predictors of functional status in psoriasis: a 1-year follow up. *British Journal of Dermatology*, 142, 899-907.

Schiaffino, K. M., & Cea, C. D. (1995). Assessing chronic illness representations: the implicit models of illness questionnaire. *Journal of Behavioural Medicine*, 18, 531-548.

Schiaffino, K. M., Shawaryn, M. A., & Blum, D. (1998). Examining the impact of illness representations on psychological adjustment to chronic illnesses. *Health Psychology*, 17, 262-268.

Schreiber, G. B., Busch, M. P., Kleinman, S. H., & Korelitz, J. J. (1996). The risk of transfusion-transmitted viral infections. *The New England Journal of Medicine*, 334, 1685-1690.

Sears, S. R., Stanton, A. L., & Danoff-Burg, S. (2003). The yellow brick road and the emerald city: Benefit finding, positive reappraisal coping, and posttraumatic growth in women with early-stage breast cancer, *Health Psychology*, 22, 487-497.

Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive Psychology. *American Psychologist*, 55.

Sharp, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, 62, 1153-1166.
doi./10.1016/j.socscimed.2005.07.0100.

- Shiffman, M. L., Di Bisceglie, A. D., Lindsay, K. L., Morishima, C., Wright, E. C., Everson, G. T.,...Everhart, J. E. (2004). Peginterferon alfa – 2a and ribavirin in patients with chronic hepatitis C who have failed prior treatment. *Gastroenterology*, 126, 1015-1023.
doi:10.1053/j.gastro.2004.01.014
- Shiratori, Y., & Omata, M. (2000). Predictors of the efficacy of interferon therapy for patients with chronic hepatitis C before and during therapy: How does this modify the treatment course? *Journal of Gastroenterology and Hepatology*, 15, 141-151.
- Siegal, K., & Schrimshaw, E. W. (2000). Perceiving benefits in adversity: Stress-related growth in women living with HIV/AIDS. *Social Science and Medicine*, 51, 1543-1554.
- Simmonds, P. (2001). The origin and evolution of hepatitis viruses in humans. *Journal of General Virology*, 82, 693-712.
- Sockalingam, S. & Abbey, S. E. (2009). Managing depression during Hepatitis C treatment. *Canadian Journal of Psychiatry*, 54, 614-625. doi: 10.1177/070674370905400906
- Soffredini, R., Rumi, M. G., Parravicini, M. L., Ronchi, G., Del Ninno, E., Russo, A.,...Colombo, M. (2004). Serum levels of Hepatitis C virus core antigen as a marker of infection and response to therapy. *The American Journal of Gastroenterology*, 99, 1738-1743. doi: 10.1111/j.1572-0241.2004.30396
- Sprangers, M. A. G., de Regt, E. B., Andries, F., van Agt, H.M.E., Bijl, R.V., de Boer, J. B., ... Foets, M. (2000). Which chronic conditions are associated with better or poorer quality of life? *Journal of Clinical Epidemiology*, 53, 895–907. doi:10.1016/S0895-4356(00)00204-3.

- Stanton, A. L., Bower, J. E., & Low, C. A. (2006). Posttraumatic growth after cancer. In L. G. Calhoun & R. G. Tedeschi (Eds.), *Handbook of posttraumatic growth* (pp. 138-175). New Jersey: Lawrence Erlbaum Associates.
- Stafford, L., Berk, M., & Jackson, H. (2009). Are illness perceptions about coronary artery disease predictive of depression and quality of life outcomes? *The Journal of Psychosomatic Research*, 66, 211-220. doi:10.1016/j.jpsychores.2008.09.005.
- Steed, L., Newman, S. P., & Hardman, S. M. C. (1999). An examination of the self-regulation model in atrial fibrillation. *British Journal of Health Psychology*, 4, 337-347.
- Sylvestre, D. L. (2002). Treating hepatitis C in methadone maintenance patients: an interim analysis. *Drug and Alcohol Dependence*, 67, 117-123.
- Sylvestre, D. L., Clements, B. J., & Malibu Y. (2006). Cannabis use improves retention and virological outcomes in patients treated for hepatitis C. *European Journal of Gastroenterology and Hepatology*, 18, 1057-1063.
- Tabachnick, B. G., & Fidell, L. S. (2001). *Using multivariate statistics*. Needham Heights, MA: Allyn & Bacon.
- Taku, K., Calhoun, L. G., Tedeschi, R. G., Gilrivas, V., Kilmer, R. P., & Cann, A. (2007). Examining posttraumatic growth among Japanese university students. *Anxiety, Stress, and Coping: An International Journal*, 20, 353-367.
- Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaption. *American Psychologist*, 38, 1161-1173.

- Taylor, S. E., & Aspinwall, L. G. (1996). Psychosocial aspects of chronic illness. In P. T. Costa, & G. R. VandenBos (Eds.), *Psychological aspects of serious illness: chronic conditions, fatal diseases, and clinical care* (pp. 7-60). Washington DC: American Psychological Association.
- Tennen, H., Affleck, G., Urrows, S., Higgins, P., & Mendola, R. (1992). Perceiving control, construing benefits and daily processes in rheumatoid arthritis. *Canadian Journal of Behavioural Science*, 24, 186-203. doi/10.1037/h0078709.
- Theunissen, N. C. M., & de Ridder, D. T. D. (2001). *Application of the self-regulatory model of illness to adherence in patients with hypertension*. Paper presented at the European Health Psychology Society/BPS Annual Conference, St Andrews, Scotland, September 5-8.
- Thompson, S. (1985). Finding positive meaning in a stressful event and coping. *Basic Applied and Social Psychology*, 6, 279-295.
- Thompson, A. J. V. (2016). Australian recommendations for the management of Hepatitis C virus infection: A consensus statement. *Medical Journal of Australia*, 204, 1-6. doi: 10.5694/mja16.00106
- Thornton, A. A., & Perez, M. A. (2006). Posttraumatic growth in prostate cancer survivors and their partners. *Psycho-Oncology*, 15, 285-296.
- Tomich, P. L., & Helgeson, V. S. (2004). Is finding something good in the bad always good? Benefit finding among women with breast cancer. *Health Psychology*, 23, 16-23.
- van Dijk, S., Scharloo, M., Kaptein, A. A., Thong, M. S. Y., Boeschoten, E. W., Grootendorst, D. C., ... NECOSAD Study Grp (2009). Patients' representations of their end-stage renal disease: relation with mortality.

Nephrology Dialysis Transplantation, 24, 3183-3185. doi:

10.1093/ndt/gfp184.

VanderZee, K. I., Sanderman, R., Heyink, J. W., & de Haes, H. (1996).

Psychometric qualities of the rand 36-item health survey 1.0: A multidimensional measure of general health status. *International Journal of Behavioral Medicine*, 3, 104-122.

Van Schuur, W. H., & Kruijtbosch, M. (1995). Measuring subjective well-being:

Unfolding the Bradburn Affect Balance Scale. *Social Indicators Research*, 39, 49-74.

Vaughan, R., Morrison, L., & Miller, E. (2003). The illness representations of

multiple sclerosis and their relations to outcome. *British Journal of Health Psychology*, 8, 287-301.

Vik, S. A., Maxwell, C. J., Hogan, D. B., Patten, S. B., Johnson, J. A., &

Romonko-Slack, L. (2005). Assessing medication adherence among older persons in community settings. *Canadian Journal of Clinical Pharmacology*, 12, 152-164.

- Wackernah, R. C., Lou, M., & Park, S. H. (2011). Retrospective chart review to assess the relationship between depression and sustained virological response from interferon treatment for hepatitis C virus. *Clinical Therapeutics*, 33, 1400-1405.
- Walker, J. G., Jackson, H. J., & Littlejohn, G. O. (2004). Models of adjustment to chronic illness: using the example of rheumatoid arthritis. *Clinical Psychology Review*, 24, 461-488. doi./10.1016/j.cpr.2004.03.001.
- Weinman, J., Wright, S., & Johnston, M. (1995). *Measures in health psychology: A users Portfolio*. London: Nelson Publishing.
- Weinman, J. Petrie, K.J., Moss-Morris, R., & Horne, R. (1996). The Illness Perception Questionnaire: A new method for assessing illness perceptions. *Psychology and Health*, 11, 431-446.
- Westbrook, T. D., Maddocks, K., & Andersen, B. L. (2016). The relation of illness perceptions to stress, depression, and fatigue in patients with chronic lymphocytic leukaemia. *Psychology and Health*, 31, 891-902.
doi.org/10.1080/08870446.2016.1158259
- Zickmund, S., Ho, E. Y., Masuda, M., Ippolito, L., & LaBrecque, D. R. (2003). They treated me like a leper: Stigmatization and the quality of life of patients with hepatitis C. *Journal of General Internal Medicine*, 18, 835-844.
- Zacks, S., Beavers, K., Theodore, D., Dougherty, K., Batey, B., Shumaker, J.,...Fried, M. W. (2006). Social stigmatization and hepatitis C virus infection. *Journal of Clinical Gastroenterology*, 40, 220-224. doi: 10.1097/00004836-200603000-00009

Appendix

Expanded Self-Regulatory Model of Illness

Copy of Online Survey's

The Participant Information sheet

The Participant Consent Form

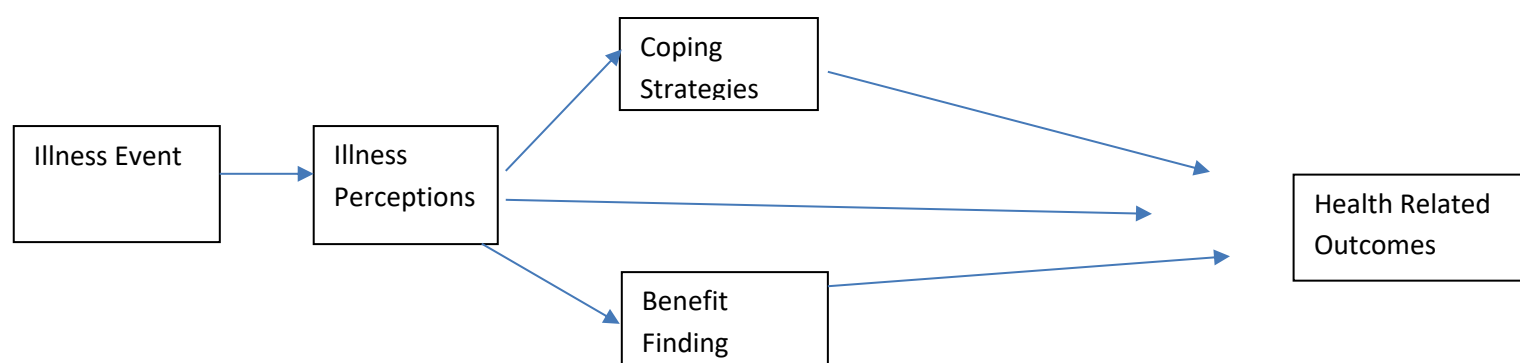
The Research Invitation Flyer

(Sent out to Patients preparing for HCV treatment at the Gold Coast University
Hospital liver Clinic)

Published Journal Papers

Expanded Self-Regulatory Model of Illness

(Leventhal et al., 1980; McMillen & Fisher, 1998).



Pre-Treatment Survey (Survey 1)

Welcome to the Hepatitis C treatment outcome prediction study. We would invite you to complete the following survey. Your valued contribution will help us to better predict Hepatitis C treatment outcomes. A second survey will be sent out to you following either your 8 week milestone blood test (if you are on the ‘triple therapy programme’), or your 12 week milestone blood test (if you are on the ribavirin and interferon combination therapy programme). The second survey will measure both treatment progress and levels of medication adherence.

This survey will take approximately 45 minutes to complete. Thank you again for assisting us with our research, it is greatly appreciated.

Section A: Questions about you and your Hepatitis C

(1) What is your email address?

(2) What sex are you?

- ☐ Male
- ☐ Female
- ☐ Other (Please specify _____)

(3) What is your date of birth? (DD/MM/YY)

☐ ☐ ☐ ☐ ☐ ☐

(4) What was your highest level of education completed?

- ☐ Primary School
- ☐ High School – Year 10
- ☐ High School – Year 12

- ☐ Diploma or Certificate
- ☐ Undergraduate degree
- ☐ Post-Graduate degree
- ☐ Other (Please specify_____)

(5) Which of the following best describes your present employment/study situation? (Please mark with an X as many boxes that apply to you)

- ☐ Full-time Employment
- ☐ Part-time Employment
- ☐ Full-time study
- ☐ Part-time study
- ☐ Home duties
- ☐ Volunteer work
- ☐ Retired
- ☐ Looking for work
- ☐ Unable to work due to illness
- ☐ Not presently looking for work

(6) Which of the following best describes your present support/living situation?

- ☐ Live with partner/spouse
- ☐ Live alone
- ☐ Live with dependent children
- ☐ Live with other family members
- ☐ Live with others (ex; flatmates/friends)
- ☐ Other (Please specify_____)

(7) What is your present relationship status?

- ☐ Married
- ☐ Single

- ☐ Divorced
- ☐ Separated from your partner
- ☐ Other (Please specify _____)

(8) Do you hold any religious/spiritual beliefs?

- ☐ Yes
- ☐ No

(9) If Yes, How would you define your religious/spiritual beliefs?

- ☐ Christian
- ☐ Jewish
- ☐ Muslim
- ☐ Buddhist
- ☐ New Age
- ☐ Other (Please specify _____)

(10) How would you describe your ethnic background?

- ☐ Australian Aboriginal
- ☐ Torres Strait Islander
- ☐ Maori
- ☐ Pacific Islander (e.g., Fijian, Samoan)
- ☐ North-West European (e.g., English, German, Irish)

- ☐ Southern and Eastern European (e.g., Spanish, Russian, Italian)
- ☐ North African (e.g., Egyptian, Libyan)
- ☐ Middle Eastern (e.g., Iranian, Saudi Arabian)
- ☐ Asian (e.g., Chinese, Indian)
- ☐ Other (Please specify _____)

(11) How much do you weigh? If uncertain, please give your best estimate

_____ KG

Or

_____ Pounds

Or

_____ Stone

(12) How tall are you? If uncertain, please give your best estimate

_____ . _____ Meters

Or

_____ Centimetres

(13) Most likely route of Hepatitis C infection?

- ☐ IV drug use
- ☐ Blood Transfusion
- ☐ Other
- ☐ Unknown

(14) Most likely length of Hepatitis C infection?

Months _____

Years _____

☐ Not known

(15) Have you ever had a liver biopsy or scan?

☐ Yes

☐ No

(16) If yes to Question 10, did the liver Biopsy or scan results indicate the presence of Cirrhosis of the liver?

☐ Yes

☐ No

(17) Have you ever been diagnosed with liver cancer? (also know as Hepatocellular Carcinoma)

☐ Yes

☐ No

(18) Have you ever had a test to find out the particular type of HCV Genotype you have?

☐ Yes

☐ No

(19) If yes, what was the result of this test? (eg, Genotype 1, 2, 3, 4, 5 or 6?)

☐ Genotype 1

☐ Genotype 2

☐ Genotype 3

☐ Genotype 4

☐ Genotype 5

☐ Genotype 6

(20) Have you ever had previous treatment for Hepatitis C?

☐ Yes

☐ No

(21) If yes, was the prescribed treatment

☐ Combined therapy using Ribavirin and Peginterferon (injection self-administered once a week)

☐ Combined therapy using Ribavirin and Interferon (injection self-administered more than once a week)

☐ Interferon monotherapy

(22) Have you ever been diagnosed with any other type of liver disease?

☐ Yes

(23) If yes, what type of liver disease?

☐ Steatohepatitis (a condition associated with fatty inflammation of the liver)

☐ Hepatitis B

☐ Other (If known, what type?)

☐ No

(24) Do you have any other medical conditions that you are currently receiving treatment for?

☐ Yes

(25) If yes, what medical condition/s are you receiving treatment for?

(1) _____

(2) _____

(3) _____

☐ No

(26) In the past week, have you used illegal recreational drugs?

☐ Yes (injectable drugs)

☐ Yes (non-injectable drugs)

☐ Yes (both injectable and non-injectable drugs)

☐ No

(27) In the past week, have you consumed any alcohol?

☐ Yes

(28) If yes, please insert in the box below how many standard drinks you consumed in the past week? (One standard drink is equal to a glass or pot of beer, or a glass of wine, or a single shot of spirits)

—

☐ No

(29) In the past week, have you smoked any cigarettes?

☐ Yes

(30) If yes, please insert in the box below how many cigarettes you usually smoke per day

☐ No

(31) Do you have any mental health condition/s that you are currently receiving medication based treatment for? (e.g. depression/anxiety/psychosis)

☐ Yes

(32) If yes, what are the name/s of these mental health condition/s?

(1) _____

(2) _____

(3) _____

☐ No

(33) Do you know what date you are starting treatment for your Hepatitis C?

☐ Yes

(34) If yes, please enter the date you are starting treatment

Day _____

Month _____

Year _____

☐ No

(35) Do you know what type of Hepatitis C treatment you will be receiving?

☐ 12 month combined Interferon and Ribavirin treatment

☐ 6 month combined Interferon and Ribavirin treatment

☐ ‘Triple therapy’ (Interferon, Ribavirin and Boceprevir)

☐ ‘Triple therapy’ (Interferon, Ribavirin and Telaprevir)

(36) Have you had the pre-treatment IL28B genotype test used to predict Hepatitis C treatment response?

☐ Yes

☐ No

(37) If yes, what was the result of this test?

_____ %

Section B: Coping with stress

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to try to deal with stress. The following questions ask you to indicate what you generally do and feel, when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress. Please respond to each of the following items by inserting a number in the corresponding box for each item from the following four choices below, which best describes what you do when you experience a stressful and/or difficult event in your life.

1 = I usually don't do this at all.

2 = I usually do this a little bit.

3 = I usually do this a medium amount.

4 = I usually do this a lot.

(38) I turn to work or other activities to take my mind off things.

☐

(39) I concentrate my efforts on doing something about the situation I am in.

☐

(40) I say to myself “this is not real.”

☐

(41) I use alcohol or other drugs to make myself feel better.

☐

(42) I try to get emotional support from others.

☐

(43) I give up trying to deal with it.

☐

(44) I take action to try to make the situation better.

☐

(45) I refuse to believe that it has happened.

☐

(46) I say things to let my unpleasant feelings escape.

☐

(47) I try to get advice and help from other people.

☐

(48) I use alcohol or other drugs to help me get through it.

☐

(49) I try to see it in a different light, to make it seem more positive.

☐

(50) I criticize myself.

☐

(51) I try to come up with a strategy about what to do.

☐

(52) I try to get comfort and understanding from someone.

☐

(53) I give up the attempt to cope.

☐

(54) I look for something good in what is happening.

☐

(55) I make jokes about it.

☐

(56) I do something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping.

☐

(57) I accept the reality of the fact that it has happened.

☐

(58) I express my negative feelings.

□

(59) I try to find comfort in my religion or spiritual beliefs.

9

(60) I try to get advice or help from other people about what to do.

☐

(61) I learn to live with it.

☐

(62) I think hard about what steps to take.

9

(63) I blame myself for things that happened.

9

(64) I pray or meditate.

☐

(65) I make fun of the situation.

☐

Section C: Hepatitis C and illness perceptions

Research has shown that individuals tend to cluster their ideas about an illness such as Hepatitis C around coherent themes or components. Collectively these themes or components make up an individual's perception of their illness. Importantly, illness perceptions provide a framework for individuals to make sense of their illness experience, which will in turn influence action and coping strategies. For the following questions, please insert the number from the scale under each question that best corresponds to your views regarding your Hepatitis C (HCV):

(66) How much does your HCV affect your life?

☐

☐ 0 1 2 3
 4 5 6 7 8 9 10
 No affect at all Severely affects my life

(67) How long do you think your HCV will continue?

9

☐

0 1 2 3 4 5 6 7 8 9 10
 A very short time Forever

(68) How much control do you feel you have over your HCV?

☐

0	1	2	3	4	5	6	7	8	9	10
Absolutely no control						Extreme amount of control				

(69) How much do you think your treatment can help your HCV?

☐

			0	1	2	3	4	5	6	7
8	9	10								
Not at all			Extremely helpful							

(70) How much do you experience symptoms from your HCV?

☐

				0	1	2	3	4	5	6
7	8	9	10							
No symptoms at all				Many severe symptoms						

(71) How concerned are you about your HCV?

☐

				0	1	2	3	4	5	6
7	8	9	10							
Not at all concerned				Extremely concerned						

(72) How well do you feel you understand your HCV?

☐

			0	1	2	3	4	5	6	7
8	9	10								
Don't understand at all clearly			Understand very							

(73) How much does your HCV affect you emotionally (e.g. does it make you angry, scared, upset or depressed?)

☐

				0	1	2	3	4	5	6
7	8	9	10							
Not at all affected emotionally				Extremely affected emotionally						

(74) Please list in rank-order the three most important factors that you believe caused your HCV. The most important causes for me:-

1. _____
2. _____
3. _____

Section D: Hepatitis C and physical health

Hepatitis C can potentially contribute to illness related symptoms that can be associated with changes in physical health and activity levels. The following questions are taken from the RAND 36-item Medical Outcomes Study and relate to your physical health. For each question please respond by marking the box that best applies to you with an X.

(75) In general, would you say your health is:

- | | |
|-----------|--------------------------|
| Excellent | <input type="checkbox"/> |
| Very good | <input type="checkbox"/> |
| Good | <input type="checkbox"/> |
| Fair | <input type="checkbox"/> |
| Poor | <input type="checkbox"/> |

(76) Compared to one year ago, how would you rate your health in general now?

- | | |
|---------------------------------------|--------------------------|
| Much better now than one year ago | <input type="checkbox"/> |
| Somewhat better now than one year ago | <input type="checkbox"/> |
| About the same | <input type="checkbox"/> |
| Somewhat worse now than one year ago | <input type="checkbox"/> |
| Much worse than one year ago | <input type="checkbox"/> |

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

- | | Yes, limited
a lot | Yes, limited
a little | No, not
limited at all |
|---|--------------------------|--------------------------|---------------------------|
| (77) Vigorous activities, such as running,
Or Lifting heavy objects. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (78) Moderate activities, such as bowling,
Or pushing a vacuum cleaner | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- | | | | |
|---|--------------------------|--------------------------|--------------------------|
| (79) Lifting or carrying groceries | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (80) Climbing several flights of stairs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (81) Climbing one flight of stairs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (82) Bending, kneeling, or stooping | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (83) Walking more than a mile | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (84) Walking several blocks | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (85) Walking one block | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (86) Bathing or dressing yourself | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

- | | |
|--|--------------------------|
| No | Yes |
| (87) Cut down the amount of time you spent on work or other activities | <input type="checkbox"/> |
| <input type="checkbox"/> | |
| (88) Accomplished less than you would like | <input type="checkbox"/> |
| <input type="checkbox"/> | |
| (89) Were limited in the kind of work or other activities | <input type="checkbox"/> |
| <input type="checkbox"/> | |
| (90) Had difficulty performing the work or other activities | <input type="checkbox"/> |
| <input type="checkbox"/> | |
| (for example, it took extra effort) | |

(91) How much bodily pain have you had during the past 4 weeks?

None ☐

- Very mild ☐
- Mild ☐
- Moderate ☐
- Severe ☐
- Very severe ☐

(92) During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- Not at all ☐
- A little bit ☐
- Moderately ☐
- Quite a bit ☐
- Extremely ☐

How TRUE or FALSE is each of the following statements for you.

- | | Definitely
true | Mostly
true | Don't
true | Mostly
know | false |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Definitely
false | | | | | |
| (93) I seem to get sick a lot easier
then other people. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (94) I am as healthy as anybody
I know. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (95) I expect my health to get
Worse | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| (96) My health is excellent | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Section E: Hepatitis C, mood, anxiety and stress levels

Please read each statement and insert in the corresponding box for each statement a number from the rating scale below which indicates how much the statement applied to you over the past week. Please note that there are no right or wrong answers.

The rating scale is as follows:

- | | |
|---|--|
| 0 | Did not apply to me at all |
| 1 | Applied to me to some degree, or some of the time |
| 2 | Applied to me to a considerable degree, or a good part of time |
| 3 | Applied to me very much, or most of the time |

(97) I found it hard to wind down

☐

(98) I was aware of dryness of my mouth

☐

(99) I couldn't seem to experience any positive feeling at all

☐

(100) I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)

☐

(101) I found it difficult to work up the initiative to do things

☐

(102) I tended to over-react to situations

☐

(103) I experienced trembling (eg, in the hands)

☐

(104) I felt that I was using a lot of nervous energy

☐

(105) I was worried about situations in which I might panic and make a fool of myself

☐

(106) I felt that I had nothing to look forward to

☐

(107) I found myself getting agitated

☐

(108) I found it difficult to relax

☐

(109) I felt down-hearted and blue

☐

(110) I was intolerant of anything that kept me from getting on with what I was doing

☐

(111) I felt I was close to panic

☐

(112) I was unable to become enthusiastic about anything

☐

(113) I felt I wasn't worth much as a person

☐

(114) I felt that I was rather touchy

☐

(115) I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)

☐

(116) I felt scared without any good reason

☐

(117) I felt that life was meaningless

☐

Section F: Hepatitis C, effects on emotions, and levels of life satisfaction

For the following questions, please think about how you have felt over the past few weeks and indicate on the following scale how relevant each of the statements have been to you. For each question please insert the relevant number from the rating scale below in the box alongside each question

The rating scale is as follows:

Not at all	1
Rarely	2
Sometimes	3
Often	4
Very Often	5

(118) Particularly excited or ☐

Interested in something

(119) Proud because someone ☐
 Complimented you on
 Something you had done

(120) Pleased about having ☐
 Accomplished something

(121) On top of the world ☐

(122) That things were going ☐
 your way

This next set of questions measures life satisfaction levels. For each of the five statements below, please insert in the box provided the number that best describes how you feel, using the scale below as a guide.

Strongly disagree	1
Disagree	2
Slightly disagree	3
Neither agree or disagree	4
Slightly agree	5
Agree	6
Strongly Agree	7

(123) In most ways my life is close to my ideal ☐

(124) The conditions of my life are excellent ☐

(125) I am satisfied with my life ☐

(126) So far I have gotten the important things ☐
 I want in my life.

(127) If I could live my life over, I would change ☐
 almost nothing

Section G: Hepatitis C and personal growth

It is possible for individuals living with Hepatitis C to experience positive personal growth. The following section will ask you to indicate how well each of the following statements describes your experience of living with Hepatitis C using the scale provided below. For each statement, please insert a number from this scale in the box provided for each statement that best describes your experience of living with this illness.

0	1	2	3
4			
Not at all like			Very
much			
My experience			like my
	Experience		

(128) This illness has taught me that I can handle anything

☐

(129) As a result of this illness, I am more afraid that bad things will happen to me ☐

(130) As a result of this illness, I am more sensitive to the needs of others

☐

(131) I have gained financially as a result of this illness

☐

(132) Because of this illness, I have learnt how good people can be

☐

(133) Because of this illness, I have a greater faith in God

☐

(134) As a result of this illness, I feel worse about myself

☐

(135) Because of this illness, I live my life more simply

☐

(136) Because of my experiences with this illness, I have learnt how to cope more effectively

☐

(137) Because of this illness, I am more compassionate to those in similar situations

☐

(138) Because of this illness, I feel more a part of my community

☐

(139) As a result of this illness, I have learnt that my family loves me

☐

(140) Because of this illness, I am a more assertive person

☐

(141) Because of this illness, I am more understanding of those in need

☐

(142) Because of this illness, I am more spiritual

☐

(143) As a result of this illness, I trust people less

☐

(144) Because of this illness, I am more aware of how much my family means to me

☐

(145) Because of this illness, I am more aware of how much people care for one another

☐

(146) As a result of this illness, I am more withdrawn from people

☐

(147) I am a more effective person because what I have gone through with this illness

☐

(148) Because of this illness, I have a greater faith in other people

☐

(149) Because of this illness, I know my neighbours better

☐

(150) Because of this illness, I find myself placing less emphasis on material things ☐

(151) Because of this illness, I show more caring to others

☐

(152) As a result of this illness, I have been harmed financially

☐

(153) Because of this illness, I feel more positive about my community

☐

(154) Because of this illness, I am more religious

☐

(155) As a result of this illness, I have lost all faith in other people

☐

(156) This illness has made me a stronger person

☐

(157) This illness has taught me that people will always be there for you

☐

(158) As a result of this event, I live more for the moment

☐

(159) As a result of this illness, it is harder for me to get close to people

☐

(160) Because of this illness, I am closer to my neighbours

☐

(161) Because of this illness, my priorities in life are different

☐

(162) As a result of this illness, I have gained material possessions

☐

(163) As a result of this illness, my life is more complicated

☐

(164) Because of this illness, I am a more capable person

☐

(165) Because of this illness, I am closer to people I care about

☐

Section H. Just three more closing questions!

(166) How did you hear about the survey?

Public or government hospital

☐

Private Hospital or clinic

☐

General practitioner

☐

Hepatitis C community support agency

☐

Other (please specify)

☐

(167) On what date did you complete the on-line survey? (DD/MM/YY)

(168) Where will you be receiving your HCV treatment?

Public or government hospital ☐

Private Hospital or clinic ☐

General practitioner ☐

Other (please specify) ☐

Hepatitis C Treatment Outcomes Survey

1

Thank you!

Hepatitis C Treatment Outcomes Survey

2

Post-commencement of treatment questions (survey 2).

In reference to Hepatitis C treatment outcomes. Can you please indicate below what blood tests (known as 'PCR' tests) you have had since commencing your Hepatitis C treatment programme and indicate what the results of each of these tests were?

(1) Week 4 PCR test result

- ☐ Hepatitis C virus was detected in my blood
- ☐ Hepatitis C virus was not detected in my blood
- ☐ PCR test was not conducted at this milestone treatment period

(2) Week 8 PCR test result

- ☐ Hepatitis C virus was detected in my blood
- ☐ Hepatitis C virus was not detected in my blood
- ☐ PCR test was not conducted at this milestone treatment period

(3) Week 12 PCR test result

- ☐ Hepatitis C virus was detected in my blood

☐ Hepatitis C virus was not detected in my blood

☐ PCR test was not conducted at this milestone treatment period

In reference to taking your Hepatitis C medication since commencing treatment

(4) During the first 12 weeks of treatment, did you take your medication as prescribed?

☐ Yes

☐ No

(5) On what date did you complete this on-line survey? (DD/MM/YY)

(6) What is your email address?

Thank You!



Participant Information Sheet

Principal Investigators

Dr Mark Edwards
Associate Professor and Research Project Supervisor
Head and Chair of Psychology
Faculty of Humanities and Social Sciences
Bond University
Gold Coast, Qld, 4229
Australia
(07) 55 95 2673

Dr Mike Lyvers
Associate Professor

Dr Peta Stapleton
Associate Professor

Mr Simon A. Langston
PhD Student Researcher
Faculty of Humanities and Social Sciences
Bond University
Gold Coast, Qld 4229
Australia
(07) 55 95 1111

Project Title: The Hepatitis C Treatment Outcome Study

Project Summary

You are invited to take part in a study designed to determine some of the physical, psychological, and social factors associated with Hepatitis C treatment outcomes. Previous research has indicated that certain physical and psychological profiles predict better treatment outcomes across a range of medical conditions. However, little is known of how these factors predict treatment outcomes in Hepatitis C. The primary objective of this research is to increase understanding of individual profiles that are associated with better Hepatitis C treatment outcomes.

What's Involved?

We are inviting individuals who are over the age of 18 years, who have a current diagnosis of Hepatitis C, who have access to the internet and a current email address, and who are planning to commence Hepatitis C treatment, to complete two confidential online surveys. Specifically, we require your email address so that we can send you a link to the second survey at the appropriate time. The first survey must be completed prior to the commencement of treatment. A link to the second survey will be sent out to participants 14 weeks after commencing treatment. The first survey should take 35-40 minutes to complete, whilst the second survey can be completed in 5-10 minutes.

Participation in this research is voluntary and any information you provide is completely confidential. Your email address and responses to the survey are not linked to any information that could personally identify you. Only the principal investigators will have access to your email address. You have the right to withdraw from the research at any time, and without penalty.

Prior to commencing the survey you will be asked to read the 'participant consent acknowledgment' section below. If you then agree to participate, you will be asked to check an acknowledgement box confirming your consent to voluntarily participate in the study. Clicking on a link directly below this acknowledgement box will lead you into the first survey.

Questions included in the online surveys will cover some of the following areas:

- Demographic information (For example, your gender, age and employment status)
- Medical information (For example, your Hepatitis C genotype, the general condition of your liver, and questions related to your general overall health)
- Psychological (For example, questions assessing how much Hepatitis C has impacted individuals lives, and further questions related to individual coping styles and general mental health)

Benefits to Participants

At regular intervals, result summaries and other relevant Hepatitis C based education and information will be posted on our website blog page. This information may be useful for individuals preparing for and undergoing treatment for Hepatitis C. Further, in recognition for the time and effort involved in participating in this research, participants who meet the eligibility criteria for participating in this study (decision at the discretion of the PhD student researcher), will be sent a AUS \$20 Amazon gift voucher after completing both the online surveys.

Storage of Collected Information

We value your privacy and right to have your information treated in the strictest confidence. All collected information will be stored electronically in a password secured file at the Bond University and only the principal investigators will have access to this information.

Potential Risks to Participants

If participating in this study results in any level of distress beyond the normal experience of everyday life, we would recommend that you consider contacting either or both of the following services:

- Lifeline 24 hour counselling on 13 11 14.
- A general medical practitioner (GP).

Ethics Approval

This research project has been granted ethics approval by the following Human Research Ethics Committees:

- Bond University Human Research Ethics Committee (HREC Reference Number: RO1359).
- Gold Coast Health Service District Human Research Ethics Committee (HREC Reference Number: HREC/11/QGC/39).

If You Have Any Questions or Concerns About This Research.....

Any Questions regarding this study can be directed to the principal investigator and PhD student researcher, Mr Simon Langston at: slangsto@bond.edu.au

If you have any concerns related to the manner in which this research is conducted, please contact either of the Human Research Ethics Committees listed below quoting the relevant research ethics approval reference details listed above:

If you have any concerns related to the manner in which this research is conducted, please contact either of the Human Research Ethics Committees listed below quoting the relevant research ethics approval reference details listed above:

Bond University Human Research Ethics Committee
Bond University
Gold Coast QLD 4229
Phone: (07) 7 55 95 4194

Or

Chair of the Ethics Committee,
Gold Coast Hospital and Health Service
Southport, Qld, 4215
Or

Patient Liaison Services
Gold Coast Hospital and Health Service
Phone: 1300 744 284

Thank you in advance for your contribution to this important study.



Participant Consent Acknowledgement

By ticking the box below I confirm that I have read and understood the information contained in both the “Participant Information Sheet” and “Participant Consent Acknowledgement” forms and in particular that:

1. I agree to participate in the study, and I am aware that I can withdraw from the study at any time. Further, I reserve the right not to provide any piece of information that I do not wish to provide.
2. Whilst understanding that I may withdraw from this study at any time, I also understand that if I do decide to withdraw that I will not be able to remove information that I may have provided earlier.
3. I understand that my involvement in the research project will involve completing online surveys both prior to and after commencing treatment for Hepatitis C.
4. I understand that my participation in this study will contribute to an increased understanding of why individuals experience differences in Hepatitis C treatment outcomes, and that the findings from this study will primarily benefit individuals undergoing Hepatitis C treatment in the future.
5. I understand the potential risks involved in participating in this study and I am also aware of the contact options should I experience any distress or discomfort related to participating in this study.
6. I understand that if I have any additional questions related to this study I can contact a member of the research team.
7. I understand that if I have any concerns related to the ethical conduct of this study I can contact either The Ethics Complaints officer at Bond University on (07) 55 95 4194 (quoting the following research project details: RO1359) or either the Chair of the Human Research Ethics Committee or the Patient Liaison Service at the Gold Coast Hospital on (07) 55 19 8211 (quoting the following research project details: HREC/11/QGC/39).
8. I agree that de-identified research information collected from me can be included in future research related activities, including the publishing of findings in thesis papers, presentation of results in relevant conferences and other public forums and may also be published in peer reviewed journals.

☐ **I acknowledge that I have read and understood this information and that I freely give my consent to participate (Please tick box if you agree)**



The Hepatitis C Treatment Outcome Study

You are invited to take part in a study designed to determine some of the physical, psychological, and social factors associated with Hepatitis C treatment outcomes. The primary objective of this research is to increase understanding of individual profiles that are associated with better Hepatitis C treatment outcomes.

We are inviting individuals who are over the age of 18 years, who have a current diagnosis of Hepatitis C, who have access to the internet and a current email address, and who are preparing for and planning to commence Hepatitis C treatment, to complete two confidential online surveys. The first survey (completed prior to treatment), should take 35 – 40 minutes to complete, whilst the second survey (completed 14 weeks post-commencement of treatment), can be completed in 5-10 minutes.

Participation in this research is voluntary and any information you provide is completely confidential. Your email address and responses to the survey are not linked to any information that could personally identify you. Only the principal investigators will have access to your email address. You have the right to withdraw from the research at any time, and without penalty.

At regular intervals, result summaries and other relevant Hepatitis C based education and information will be posted on our website blog page. This information may be useful for individuals preparing for and undergoing treatment for Hepatitis C. Further, in recognition for the time and effort involved in participating in this research, participants who meet the eligibility criteria for participating in this study (decision at the discretion of the PhD student researcher), will be sent a AUS \$20 Amazon gift voucher after completing both the online surveys.

If you have any questions regarding this research, please contact Mr Simon Langston at slangsto@bond.edu.au

If you are interested in participating in our research, you can access the online survey at:

<http://hcvstudy.bond.edu.au>

Thank you in advance for your contribution to this important study.

